

**UTILISATION OF HOME-BASED CARE SERVICES BY
THE COMMUNITY OF CAPRIVI REGION IN NAMIBIA**

A mini dissertation

By

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DECLARATION

I, Kanku Tshibola Ndalambo, declare that this dissertation is my work. It is being submitted for the degree of Masters in Public health at the University of Limpopo, MEDUNSA Campus. It has never been submitted before for any degree or any examination at this or any other institution.

Kanku Tshibola Ndalambo

Date

DEDICATION

I dedicate this study to my brothers and sisters, Jean Claude, Odette, Arnold, August, Patrick, Isabel, Mwabana, Adele, Jojo and Fiston.

To my wife Claris Muchanga and all my children.

To my late father Kanku Kaboto and my late mother Tshibile Juliene

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ABSTRACT

Background

Namibia is one of the country most affected by HIV/AIDS epidemic in the world and in Sub-Saharan Africa with an adult prevalence of 19,7 %, and 210.000 people estimated to be living with HIV/AIDS at the end of 2003. The Caprivi region adult prevalence in adult pregnant women is estimated at 43%.

The health care services are overstrained with patients and home-based care (HBC) is seen a possible solution. The scale up of HBC and expansion of coverage to patients has lessened the burden of public hospitals to deal with all these chronically ill patients. The challenges that volunteers are facing impact in the quality of care people living with HIV/AIDS receive.

Objectives

This study assessed the utilization of home-based care service, knowledge and perception of People living with HIV and AIDS (PLWHA) toward home-based care services. The views of volunteers towards home-based care service are also reported.

Methods

This is a qualitative study that utilized Focus Group Discussions (FGDs) for the home-based care-givers and in-depth interview with the clients accessing antiretroviral treatment at Katima State Hospital. A total of four focus group discussions were organized with care-givers comprising 31 adult participants (15 males and 16 females) and 18 in-depth interviews were conducted with the people living with HIV and AIDS accessing antiretroviral treatment (ART) at Katima State Hospital. All FGDs were tape recorded and one-to-one interview was hand written.

Result

The study demonstrates that most of the participants have positive attitudes toward utilization of HBC service. However, few people are still afraid to disclose their health status. In general, the community participation has tremendously reduced stigmatization.

The self-reported health status by the HBC givers in order to have access to nutrition support may have played a role in reducing the stigma associated with HIV and thus increased the number of people utilizing the HBC service.

The HIV-positive participants valued the assistance received from the volunteers and volunteers appreciate the training received to enable them to undertake their duties with more confidence. The dress code of volunteers when visiting patients was perceived to disclose HIV status but did not influence patient attitude to access the service.

Conclusion

The improvement in community knowledge about HIV and HBC service has enhanced the positive attitude toward utilization of home-based care service which has consequently reduced the stigma associated with HIV. Advocacy is required to improve the working condition of volunteer care-givers home-based care by policy markers. The collaboration between different stakeholders will advance and sustain the HBC service in focusing on prevention of HIV infection.

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ACRONYMS AND ABBREVIATIONS

AIDS	-	Acquired Immunodeficiency syndrome
ARV	-	Antiretroviral
BMS	-	Bristol Myers Squibb
CBAO	-	Community Based AIDS Organization
DED	-	Germany Development Programme
FGD	-	Focus Group Discussion
GDP	-	Gross Domestic Product
HAART	-	Highly Active Anti-retroviral Therapy
HBC	-	Home -Based Care
HIV	-	Human Immune Virus
KAP	-	Knowledge, Attitude and Practice
MOHSS	-	Ministry of Health and Social Services
NDHS	-	Namibia Demographic and Health survey
NEDICO	-	New Dimension Consultancy
NGOs	-	Non-Governmental Organization
NRCS	-	Namibia Red Cross Society
NSPH	-	National School of Public Health
PLWHA	-	People Living With HIV and AIDS
PMTCT	-	Prevention of Mother to Child Transmission
PWA	-	People with HIV/AIDS
REPC	-	Research and Ethical P Committee
RMT	-	Health regional Management Team
SADC	-	Southern Africa Development Community
SIAPAC	-	Social Impact Assessment and Policy Analysis Corporation
STI's	-	Sexual Transmitted Infections
WHO	-	World Health Organization

CHAPTER 1 – INTRODUCTION AND BACKGROUND

1. Introduction

The Southern Africa region is believed to be home to 32 % of the world's population living with HIV and AIDS (PLWHA) and accounts for 34 % of all AIDS deaths (UNAIDS 2006). The majority of adults (age 15 or higher) living with HIV are women. The impact of mortality due to HIV/AIDS has given rise to lower life expectancies, higher death rates, lower population and growth rates, and more changes in the distribution of population by age and sex than expected. In sub-Saharan Africa alone, the epidemic has orphaned nearly 12 million children aged less than 18 years (UNAIDS 2006).

According to Namibia's 2001 population and housing survey census, Namibia has a population of 1,830,330 million people with an annual growth rate of 2,6 %. It consists of 942,572 females and 887,721 males, with relatively young generation aged less than 15 years accounting for 43 % of the population and only less than 4 % are over the age of 65 years (Namibia Census Report, 2002).

Namibia is one of the countries with the highest HIV/AIDS prevalence rates. The prevalence is about 20 % and Caprivi region is the hardest hit with a prevalence of 43 % (Sentinel Survey, 2004). At the end of 2003, there were 210,000 people estimated to be living with HIV/AIDS in Namibia, or more than one in five adults. Although recent evidence shows a possibility of decline in the prevalence, the epidemic already posed significant challenges to this middle-income country, with high levels of unemployment and income disparity as these may further increase the spread of diseases such as HIV/AIDS (UNAIDS, 2004).

The HIV epidemic is affecting every aspect of the Namibian society (SIAPAC, 2006). The impacts comprised of a reduction in the population growth rate, alterations to the demographic structure of the population, economic losses through a reduction in gross domestic product (GDP), as well as broader societal change as a nation comes to terms with its losses, and the need to care for the infected and affected becomes visible.

Although the first case of AIDS in Namibia was only identified in 1986, the disease has since become an extremely serious public health problem and remains one of the major challenges to the country's socio-economic development. Namibian's high risk for HIV/AIDS groups includes mobile populations (migrant workers and truck drivers), young women and girls along transportation routes, sexually active youth, uniformed service members, and commercial sex workers (SIAPAC, 2006).

1.1 Background

Caprivi region is situated in the extreme northeastern part of Namibia, about 1,300 kilometers from the capital city Windhoek. It is 400 kilometers long and 80 kilometers wide and is the only point in Africa where five countries (Angola, Botswana, Namibia, Zambia, and Zimbabwe) meet, which contributes to the complexity of the region in terms of cross border activities. The antenatal HIV rates in the bordering towns are: 45 % in Victoria Falls/ Zimbabwe; 40 % in Kasane/ Botswana, and 31 % in Livingston, Zambia respectively. Caprivi region has the highest HIV prevalence in Namibia of 39.4 %, compared to the country's average rate of 19.6 % (Republic of Namibia Sentinel Survey, 2006).

Caprivi has a population of 90 444 people according to the population projection of 2008. The influx of people to Caprivi from foreign countries is very high, including the truck drivers who use the Trans-Caprivi highway from the port of Walvis Bay to other Southern African Development Community (SADC) countries. This has escalated the situation as the bridge joining Namibia to Zambia was recently opened. The diversified customs and traditional beliefs (such as witchcraft) tend to affect the communities' perception towards HIV/AIDS and HAART, which are also predictors of poor adherence to the ART programme. The general population is illiterate and this is thought to be an important factor in their view about HIV-infection, treatment and adherence. More than half of the adolescents in the region have been reported to be involved in sexual relationship, which includes 3.1 % of those below 10 years (Mabuku, 2005).

The Ministry of Health and Social Services (MoHSS) conducted a National Demographic Health Survey in 2000 (NDHS) on the thirteen regions and reported that there is an increase in the knowledge in the general population that a healthy looking person could be infected with HIV and transmit the disease to others. The same survey showed that 95 % of the respondents in the Caprivi region said they never had a family member who had died of AIDS but they attributed most deaths to witchcraft (Namibia Demographic Health Survey, 2000). This shows that there is a high level of denial among the general population. There are still people who prefer to consult traditional healers for treatment than going to the hospitals or clinics. Due to the high unemployment rate and poverty, women end up having sex with men in exchange for money. Multiple partner relationships are still being practiced in the region, while some men have more than one wife and other sexual partners. Males have more control of sexual relationship than women (Namibia Demographic Health Survey, 2006).

It is reported that Namibia has an estimated 15 000 children living with HIV and about 57 000 have been orphaned by AIDS while 16 000 deaths are due to HIV/AIDS and HIV is being spread primarily through heterosexual sex (UNAIDS, 2003). HIV and AIDS has become the number one cause of deaths in Caprivi region. The disease has orphaned many children and many families are left without breadwinners. Health facilities are overcrowded with patients resulting from HIV related-cases (UNAIDS 2003).

In 2003, the Namibia Ministry of Health and Social Services signed an agreement with Bristol Myers Squibb (BMS) company and Secure the Future Foundation (STF) for the implementation of antiretroviral therapy at Katima Mulilo State Hospital under the programme called "Mapilelo project". It was a three year programme sponsored by Bristol Myers Squibb and Secured the Future Foundation aimed to deliver highly active antiretroviral treatment (HAART) and prevention of mother to child transmission (PMTCT) services. The community based support structures like home-based care; food security, voluntary counseling and testing (VCT), and social mobilization were also initiated. The goal of the Mapilelo project was to promote community acceptance and support the people living with HIV and AIDS (PLWHA) and also to promote community-based services including psychosocial support through voluntary counseling and testing and support groups.

MAP OF NAMIBIA (Courtesy of the CIA World factbook, 2007)



1.2 Problem statements

Caprivi region has the highest HIV prevalence in Namibia and of the 90 444 projected populations in 2008; only 22 000 live in the urban area while the rest live in rural areas. The HIV prevalence for Caprivi region is estimated at 39.4 % (Namibia MoHSS Sentinel Survey, 2006) while the country's prevalence is estimated at 19.6 % (Namibia MoHSS Sentinel Survey, 2006). Caprivi region has also experienced the fourth largest increase in number of HIV/AIDS deaths in the world from 1999-2001 (Namibia Census, 2001). The region has one district hospital named Katima Mulilo State Hospital, which is also the only referral hospital in the region. The region has three health centers and 25 clinics. The Katima district hospital has all the basic services such as out-patients' department comprising of antiretroviral treatment clinic (ART clinic), and casualty department, the laboratory and radiology departments, maternity, male and female general medical and pediatric wards and tuberculosis wards with an operational theatre.

The hospital is overcrowded by chronically ill patients who basically could have benefited from being cared for at home-based service, which explains the under utilization of home based care programme. In 2005, Katima State Hospital had link with community-based structures for the support of patients on antiretroviral treatment (ART). Patients are usually referred to either the community health centers or hospitals and the formal method of referral is by sending patients with their health passports. This is not a strong approach of referral as some of the patients would not reach the referral point due to many factors like fear of being stigmatized by other members of the community.

The under-utilization of home-based care programs or services by the communities has resulted in the overcrowding of the only state hospital in the region, which has also led to an increase in health care expenditures, burnout of the healthcare providers and poor quality of health care service delivery. The initial problem of home-based care was due to the fact that there was still high degree of denial from some community members who perceive that the hospital was the best place where care should be provided and not to be nursed at home by care-givers (Namibia MoHSS Home-Based Care handbook, 2001).

1.3 Study justifications

In 2004, the National HIV prevalence rate amongst pregnant women in Namibia was 19.7 % with the highest rate of 42.3 % in Caprivi region. HIV/AIDS has seriously impacted on labor supply, human capital and savings and has as well contributed to a decline in productivity. HIV has not just infected individuals but has also affected members of the family, friends, and the community. It has impacted negatively on the national economy (Third Medium Term Plan 2004-2009). The Government of Namibia in the second medium plan had planned to strengthened community-based support for both HIV/AIDS and Tuberculosis (TB) patients using the direct observe treatment (DOT's) through home-based care services in all the 13 regions of the country. The increased health care expenditures; burnout of healthcare provider and poor quality of health care services being provided because of the overcrowded hospital wards could only be eased by the utilization of home-based services by the community.

No research has been conducted of this kind in Namibia, taking into account the importance and impact of the epidemic. It is hoped that the results from this study could assist the policy makers and programme managers come up with appropriate approaches on how to sustain and support the utilization of home-based care (HBC) services.

Recommendations will be made to the government of Namibia on how to improve the quality of care in the community for people living with chronic diseases.

1.4 Research goal

- To explore the knowledge of PLWHA and care-givers about home-based care services in Caprivi region.

1.5 Research questions

- What is the current situation with regard to utilization of home-based care in Caprivi region?
- What is the knowledge of PLWHA towards home-based care services?

- What is the view of home-based caregivers towards home based care service in the Caprivi?

1.6 Research Objectives

- To assess the utilization of home-based care services by PLWHA in the Caprivi region in Namibia.
- To assess the knowledge and perception of PLWHA towards home-based care services.
- To assess the view of home-based caregivers toward Home-Based Care services.

CHAPTER 2 - LITERATURE REVIEW

2.1 Introduction

The HIV/AIDS epidemic has become a serious health and development problem in many countries around the world. The hardest hit is the Southern African region, where Namibia belongs. In Namibia, communities still believe very much in hospital care (Namibia Ministry of Health Home-Based Care Handbook, 2001). This attitude needs to be changed through intensive awareness campaigns, for the communities to understand that it is important for them to care and support people living with HIV/AIDS. As there is no cure for AIDS, hospitals and other health facilities provide symptomatic treatment for many opportunistic illnesses associated with HIV infection. However, the willingness and acceptance of families/communities to be involved in the provision of care and support will depend on the information and education provided to them. The understanding of the disease will reduce fear and minimize stigmatization and rejection as well as discrimination at all levels in Namibia MoHSS Home-Based Care Handbook, 2001).

In Namibia's Ministry of Health, home-based care handbook HBC service is defined as a form of care given to sick people in their own homes. It means the practices people might do to care for themselves or the care given to them by family, volunteers, and members of NGOs or by health care workers. The main aim of the programme is the promotion of the philosophy of providing care to PLWHA in their home, mobilization of family/community resources for home/community care support, provision of information, education and communication services to HIV/AIDS clients, their families and wider community so as to promote sustained positive behavioral change to reduce transmission. The other aim is to reduce the hospital bed occupancy rate and provide counseling to the family in caring for terminally ill people at home.

2.1.1 Community attitude towards PLWHA

An evaluation of activities of community home-based care rendered by a certain PLWHA NGOs in Alexandra Township in South Africa revealed that, despite the increased number of

HIV-positive people, community attitude towards PLWHA remains visibly negative. The main NGOs operating in the area are not advertised to minimize the negative attitudes towards PLWHA and their families who access their services.

It has been shown that Alexandra is one of the communities with the highest level of sexual violence against women in South Africa. In terms of home-based care services, an evaluation shows that cost effectiveness of HBC services correlate to the use of community volunteers who are HIV-positive or PLWHA themselves when compared to service provided by public facilities and other NGOs, the reason was that PLWHA NGOs are more sensitive to the needs of PLWHA (Chimere, 1998).

In a study conducted in Canada on impact of support services provided by a community-based AIDS-service organization (CBAO) on persons living with HIV/AIDS revealed that high users of CBAO were single, living alone and reported poorer health and that the community-based services reduced their isolation and improved their quality of life. The increase of capacity of service providers can enhance health related quality of life (Crook *et al.*, 2005).

A cohort study conducted in Uganda to assess the social outcomes, both positive and negative, of a home-based antiretroviral treatment program, revealed that discrimination by the community of patients on antiretroviral therapy was negative social outcome of home-based program (Lugada, 2007).

A study, which was done on the accessibility of home-based care by PLWHA in France Baard district revealed that factors that hindered accessibility of home-based care included lack of acceptance by people in the community which makes it very difficult for volunteers to execute their duties. Ignorance and illiteracy on the side of the community with regard to HIV/AIDS constitute barriers which lead denial about HIV/AIDS. On the other hand, disclosing their HIV-positive status leads to ostracism and rejection by the community, which makes it more difficult to reach PLWA (Beukes, 2005).

A study conducted by Smith in North of Namibia on HIV risk assessment and HIV testing

intention revealed that personal experience and belief impacted the perception of the personal risk of contracting HIV. It also revealed that people who have discussion or experiences with people living with HIV are more likely to seek an HIV test. The study shows that it is not the perceived risk to contract HIV which motivates people to seek for HIV test but the education and information received, which in turn influence the intention to undergo HIV-testing. It was also reported that age did not influence the behavior of testing and that the negative belief, peers, witchcraft, looking sick, perceive seriousness did not contribute to the perception of other's risk (Smith, 2006).

Another study conducted to explore the attitudes of Japanese-American families toward community-based long-term care services and also to determine factors that influence community-based service utilization among Japanese-American families showed that families played an active role in sustaining and augmenting the care giving, regardless of living environment, the more involve the family, the better the care. The study shows that sustainability of care for chronically ill patients depend on the level of family commitment to care for their own patient (Young, 2002).

An enhanced patient evaluation study in Southern Africa by family health international (FHI) on stigma revealed that community support services have no influence in reducing stigma and that the influence of home-based care on adherence declined between 12 months and 18 months, an indication that after the first year of the programme, home-based care may not be the most effective outlet for support (Jeanette, 2007).

The HBC handbook revealed that in Namibia due to high degree of denial from some community members, people perceive that the hospital is the best place where care should be provided. Some of activities rendered by home caregivers include home visit to provide physical, medical, social, spiritual and material support, to increase community awareness about availability social welfare support, to give health education, nutrition, positive living with HIV/AIDS and condom promotion and to care for orphans and vulnerable children and counseling client, family and the caregivers at home level (Namibia MoHSS HBC Handbook, 2001).

2.1.2 The continuation of health care

The Kenyan National Home-based care programme and service guidelines by the National AIDS/STD control programme in the Ministry of Health states that to facilitate the continuity of the patient's care from the health facility to the home, it is necessary to empower PLWHA, their family, and the community with the knowledge needed to ensure long-term care and support. It also include activities such as clinical services, nursing care, counseling, and social support and represents a continuum of care, from the health facility to the community, to the family, to the individual infected with HIV/AIDS and back again. In other words, it is a holistic, collaborative effort by the hospital, the family of the patient, and the community to enhance the quality of life of people living with HIV/AIDS (PLWHA) and their families (Kenya MoH HBC Guideline, 2002).

A review of models of community home-based care for people living with HIV/AIDS in Southern Africa and range of service provided to clients has described different type model of community care and the comprehensive home care programme where well established organization and NGOs provide the service after care givers have been trained to support many patients. The cost effectiveness is still questionable as there is not conclusive data to support it. However, the understanding is that the training of these care givers contained supportive counseling, cleaning and dressing of wounds, supervision of medication taking; direct observe treatment (DOT), pain management and treatment of opportunistic infection, all these in a certain way help to improve care of patients. This type of care requires a good networking with different health institutions, welfare department and schools that are becoming more complicated and less effective. In the comprehensive home care, some activities can be incorporated such as prevention, voluntary counseling and testing, health education and destigmatization (Busisiwe, 2005).

The Kenya study that investigated care giving to people with HIV-related illness and the socio-economic status of their caregiver indicated that there are significant differences in living arrangements, wealth, income and expenditure between caregivers and non-caregivers. HIV-caregivers were found to live in larger households and were also more likely to live in households with a large number of children below the age of 15 years. Whereas a high

proportion of HIV-caregivers were ranked highly in terms of wealth status, differences in per capita income, however, expenditure were not significant when household size and other factors were accounted for. Another key finding was that a higher proportion of HIV-caregivers relies on salaries as their main source of income compared with non-HIV caregivers. Older people providing care may in longer term be economically disadvantaged due to their large number of dependents (Chepngeno, 2008).

A retrospective study conducted in Sweden in 2007 on end-of-life care and the pattern of utilization of health care services revealed the use of different combinations of health services at the end-of-life: hospital care, primary care and care at home. It was found that majority of people used hospital-based care at the end of life and this care was not the same for everybody as it was dependent on demographic, type of illness characteristics and social environment. It was found that the acute care provided at the hospital to older people was not ultimate or necessarily required during the end-of-life period as the problem at this period is the age and chronic condition of the patient (Jakobsson, 2007).

A cohort study conducted to investigate medical health care utilization following the decision about long-term care at home versus special accommodation of older people in Sweden revealed that from the 1079 participants followed in the study for 3 years, the majority of people who received care at home were more younger and showed increased utilization of medical healthcare in comparison with older people who were in special accommodation. It was also found that under the long-term care, the earlier the detection and treatment of medical condition by health professionals, the lesser the need for medical healthcare. The utilization of outpatient service was more for the patients receiving care at home than those in special accommodation. This does not mean that the special accommodation is the best solution for everyone. The age did not influence the utilization of medical service but the environment where a patient was given care did. If older people are cared at home it will imply an increase in utilization of medical healthcare (Condelius, 2009).

A quantitative study was conducted in Potchefstroom in South Africa on community-based care for children with HIV. The majorities of the participants (non-professional caregivers) in the district were females (88 %) and aged between 19 to 30 years (47 %).

The study showed that non-professional caregivers displayed good general knowledge regarding HIV/AIDS, 73-94 % of care-givers knew the methods of HIV transmission and half knew the HIV prevention approaches with regards to children. The study showed that for a good quality of care at home, the caregivers need training which empowers them with necessary knowledge and skills to ensure that a child with HIV receives quality care (Van Graam et. al., 2007).

2.1.3 Role of community volunteers

The role of home-based caregivers is that of visiting and caring for chronically ill patients, disabled, the weak and the elderly people in order to prevent the stigma. The volunteers do provide help with household chores, such as fetching water, collecting firewood, cooking their food and feeding them. They facilitate the referral of patients to the social worker, health facility, raise and donate funds to take patients to the hospital, encourage community to go for testing, give them information on PMTCT, VCT and HAART. In addition, they offer psychosocial support, advice, and encourage patients to live positively. In the provision of service, it is important to identify needs of people who require to be enrolled in the home-based care that are specific to the PLWHA, to the family, and to the community within which the PLWHA lives. There are different needs like physical, spiritual/pastoral, social, or psychological, which vary from person to person and from one community to the other. These needs should be identified when a PLWHA is being enrolled into a home-based care program for effective service to be provided (Namibia MoHSS Home-Based care Handbook, 2006).

The survey conducted in New York to assess the client satisfaction about comprehensive home healthcare demonstrates that there is need of such a comprehensive service as more people felt comfortable to receive most prophylaxis for HIV-related treatment in home settings. The survey shows that patients were satisfied with the provision of care in the home setting because the majority of care can be delegated to the paraprofessionals (Carr, 1990).

In a study assessing the patients satisfaction with home healthcare services for clients with HIV in 1995, HBC was found to be appropriate and feasible in the era of HIV because having health home-based care to alleviate hospital the burden as long as the quality of care is

maintained. It is important that caretakers receive the appropriate in-service education and supervision to enhance their skills profile (Foley et. al., 1995).

The study conducted in Caprivi region in Namibia by Thomas in 2004 shows that localized and participatory approach is necessary to promote the involvement of other household members and community's members in contributing to caring duties.

The same study reports that the psychological well-being of the patients was influenced by the way others view the patient. As some patients start recovering and contributing to the household activities, the better the patient feels accepted and improves the well-being, and the less the stigma. The compassion and sympathy towards ill patients was evident at the early stage of the disease but long term HIV and AIDS makes caring a burden upon household livelihood security and intra-household relation as the patient condition deteriorate over time. It is important that people should get tested early and access antiretroviral treatment when they are not ill to reduce the cost of long term care. The author recommended that local initiative can be developed in order to decrease the burden of care and subsequently the stigma and neglect of ill people (Thomas, 2006).

It is known that the provision of health service closer to people's home helps to promote the sustainability of care. In the study conducted by Sadler in 2005 revealed that the continuum of care combines the medical and nutritional treatment with home and clinic-based support. By decentralizing the treatment sites, it decreases the barriers to access of treatment at the same time reduce the default to treatment and encourage community participation. The use of treatment of acute malnutrition and provision of high nutritious food in the community instead of the hospital can be used as an entry point that provides an opportunity to healthcare workers to establish trust with community and the mechanism which allows people infected and affected with HIV to access the support whilst minimizing stigma. If community-based care is well understood by the community, the participation of this community will lead to cost effectiveness and sustainable home long-term care. It was demonstrated that utilizing food nutrition programme as entry point by involving close family members of the patient with HIV, and increase their productivity will enhance trust and reduce stigma (Sadler, 2005).

A Study on the role of volunteers in home-based care in South Africa indicated that HIV/AIDS accounts for between 25-40 % of deaths in South Africa and there are more women caring for AIDS patients with low male involvement and a substantial part of home-based care costs are borne by volunteer caregivers who are largely poor, infected and affected women thus exacerbating their burden. Akintola (2005) reported that the role of volunteers is to provide patients and their families with information on resources that are available in the community and to relieve HIV/AIDS affected families of the burden of care by teaching family members skills and knowledge on the various issues that relates to care. (Akintola, 2005)

A literature review of articles on the pattern of access to community palliative care services in 2009 shows that the utilization of home-care service depend on the presenting symptoms. The hypothesis is that older people have different needs and sickness which need a referral from a general health professional to the home-care, and older people's attitudes towards palliative care may affect their use of service. It was revealed in another study that the use of home-care depends on the age of the caregivers; as the younger the caregivers, the greater the support needs, or greater effectiveness in obtaining help. But from all these studies, there were age related influence on utilization of the palliative. On a gender related effect, some studies demonstrated that gender does not affect the utilization of palliative care but for those studies that did identify a difference, the majority reported that women were more likely to utilize the palliative home service compared to men but no clear explanation was given for this tendency. On ethnicity, it was found that general practitioners were more likely to refer members of ethnic groups to home-care than inpatients hospice because of the emotional and feeling that home care is more compatible with the family wish to care for the loved one at home. It was also found that the socioeconomic situation impact in the utilization: the income level, the higher the income, the easier it is to access care. On education level, some studies found that the lower the education level, the greater the need of palliative care and that those who own homes and live in urban areas are less in need of palliative care but can access care than those in rural areas (Walshe, 2009).

The qualitative study conducted in Lesotho, revealed that some home-based caregivers perceive that care giving responsibility includes accompanying the patients to the hospital to

obtain medical treatment. Some caregivers found hospital support predictable and responsive to the emergent needs at home. The study findings suggest that while the primary goal of home-based care is the reduction of hospitalization, there is also a risk that reduced utilization might erroneously be attributed to functioning of home-based care programs, while in actual fact, it conceals the unmet needs of the patients and their caregivers. The study concludes that effective home-based care depends on uninhibited communication about the patients' illness between the various actors involved in the provision of care in the two domains of care at home and hospital (Mokhantšo et. al., 2008).

2.1.4 Challenges faced by community volunteers

The volunteering work has some successes and challenges. An assessment conducted in Namibia in 2004, shows some of the major challenges faced by volunteers when performing their duties: poor relationship with the community, lack of food, detergents, medication and transport to facility, lack of training and supportive supervision, lack of recognition and remuneration. On poor relationship, the assessment emphasized on lack of communication and misunderstanding related to stigma of HIV/AIDS, TB and difference in the understanding of concept of volunteerism. Volunteers reported that they feel misunderstood, insulted, rejected by their communities (NEDICO, 2006).

The Kaiser Foundation examined the challenges facing Swaziland's home-based caregivers and reported that the country has few care givers who are poorly paid but they have a major role to play in nursing the people living with HIV/AIDS. The reason is the negative attitude of the community towards the caring job and the traditional view of gender which often prevent men from becoming caregivers. Some of the caregivers' duties include feeding, washing, dressing and reading to people living with HIV/AIDS, as well as imparting health advice and offering companionship. Many of them also face the challenges of working in rural areas where it is necessary to travel long distances on dusty or muddy roads, according to one of the care givers report. The recommendation of the report is that there should be attitudinal change towards job type and gender (Henry, 2006).

A study was conducted on AIDS and palliative care in South Africa with the purpose of examining the major challenges involved in providing quality end-of-life care to people with AIDS in South Africa, as many people die of AIDS in South Africa as a result of limited access to antiretroviral treatments. The finding was that AIDS patients need palliative care but there are still some challenges like, ineffective control of pain, integration of community-based home care model that relies heavily on community caregivers to meet the needs of people dying of AIDS, and the living conditions of AIDS patients and their families, and AIDS-related stigma remain a challenge (Demmer, 2007).

Mapping of community home-based care services in five regions of Tanzania mainland by Pathfinder international in 2006 identified some of the gaps, and challenges for provision of good home-based care services (HBC) as lack of confidentiality, lack of work material like gloves, inadequate and irregular supply of medicines. Other client and family related challenges are fear to disclose their HIV positive status and some knowingly, spreading HIV (Pathfinder International, 2006).

The study conducted in Entabeni, South Africa on supporting people with AIDS pointed to multiple needs of AIDS patients and their caregivers. At material level, people spoke of shortages of money, food and affordable transport to clinics or hospitals. At practical level, people have difficulty working without many of the basic resources for home nursing, such as gloves, bedding or clean accessible water. The burden of care was often the final straw for already over-extended women. At emotional level patients and caregivers felt isolated in a community where stigma made people reluctant to disclose their HIV status. However, the community still has some volunteer health workers, who played a central role in facilitating the informal home-based care of people with AIDS. Their work involved walking long distances on foot, often up steep hills, and often in conditions of searing heat, to households which might be several kilometers from their villages (Campbell et. al., 2007).

A South African study that evaluated the home-based care services showed that the success of the HBC services is connected to the combination of funds allocated for the implementation, advocacy, home visits, technical support, support groups and comprehensive

care practices. A good monitoring and evaluation system should also be in place to track the progress (Russell et. al., 2000).

A qualitative/quantitative assessment of a home-based care services in Maputo, Mozambique revealed that the main reasons for refusing home visits or not taking part in it by both patients and caretakers, are connected to stigma and discrimination. Accepting visits may be seen as a way of publicly revealing the patient's HIV/AIDS status to his community and family. However, home-based care services are seen to be having positive effects in combating stigmatization by enlarging the visibility of the epidemic before the community and society (Benedetti et. al., 2004).

2.2 Conclusion

There is a need for communities to know and understand the activities undertaken by home-based care services. That can be achieved by empowering the communities through education and also volunteers need community support, trainings and rewards.

CHAPTER 3 - METHODOLOGY

3.1 Introduction

This was a qualitative study that utilizes the focus group discussion (FGD) of care givers and one-to-one interview with PLWHA (KI). The FGDs refer to qualitative method that gathers people of homogenous background or experiences to discuss a specific topic of interest to the researcher (Dawson et. al., 1993). Key informants are people living with HIV/AIDS (PLWHA) who access antiretroviral therapy at Katima Mulilo State Hospital.

The interview guides were pre-tested in a FGD role play, conducted on the first day of research orientation session at Mapilelo clinic. The researcher explained to participants (4 PLWHA and 3 volunteers) the aim of pre-testing the questionnaire and at the same time demonstrated to the moderators and field assistants how to conduct FGDs and how to collect field notes. At the end of the session, some adjustments were made to the meaning of some words in the local language version of the questionnaire. At the same occasion, the questionnaire was read to the group and no adjustments were made. The researcher conducted 2 extra sessions with the moderators and the field assistants afterwards.

All the members of the field team were contacted in advance and researcher had to explain their roles, the purpose of the study and how he intends to collect data.

The researcher conveyed a first meeting on 9th August 2008, two weeks before data collection but due to commitment of most members, the meeting did not take place.

Members selected to be part of the research were:

- A Registered nurse who once conducted a focus group discussion in a qualitative study on factors influencing adherence to antiretroviral drugs in the resource limited setting in the Caprivi region. She was the moderator of the FGD.
- Two community counselors: one male as an assistant moderator and a female as an observer for the first FGD.
- One volunteer male as an observer for the second FGD.
- Doctor from ART clinic to be part of orientation and to organize the role play of FGD.

- Home-based care coordinating officer from the Red Cross Society to be part of the team helping to organize the people to be interviewed and facilitated the introduction of the field team.

Orientation meetings process

The second meeting was conducted 3 days before the volunteers' refresher training where we were supposed to collect data. Unfortunately the nurse who was supposed to conduct the FGD was not available on that meeting as she was on vacation leave. It was confirmed that the first training will take place on 25th August and the second training will be on 15th September 2008 at Cheshire home.

On Friday 22nd August 2008 around 14H30, all the field team members gathered in my office situated at Katima Mulilo State Hospital in the Mapilelo clinic.

All seating arrangements were ready and the orientation meeting started. Researcher welcomed all members present and thanked them for their time. The researcher introduced himself and other members present; five people attended the meeting plus the researcher, two community counselors, one doctor, one coordinator of HBC from NRCS, and one volunteer. The purpose of the orientation was explained and guideline for FGDs were presented by the researcher to the team and some input from the group were made and corrections done where necessary. Issues discussed were consent forms, confidentiality, respect of people's opinion, not to be judgmental about participant's views and opinion, freedom of participation, review of equipment to be used for recording and the camera for video. At 15H20, the researcher designed a FGD, to demonstrate how the FGD is conducted as role play. The team members were participants and he introduced himself and allocated specific numbers for identification to participants.

The researcher started the first question and demonstrated how to probe, how to attract attention of all participants, how to show that you are listening to the respondents. Two people were selected as moderators of the forthcoming FGDs, they then practiced at the same spot and few critics were made. The questionnaires were given plus guideline of conducting

FGD to the two chosen moderators to practice at their convenient time as the collection of data was to be conducted three day later. Around 17h30 the researcher thanked everyone who participated and the closed the session.

Field session report

The research team arrived at Cheshire home at 10h00 hours in the morning of 25th August 2008 at the place of the workshop. The team found participants in their sessions, 20 minutes later, the research team was welcomed by the regional Red Cross Manager who introduced the team to the participants and explained the reason of the visit as they were already informed early that morning. Then HBC officer requested the researcher to introduce his team. The team met 30 volunteers who were attending the training, 8 males and 22 females. The researcher started by greeting all the participants and introduced himself again and his entire team. He introduced in details the research title, objectives, process of data collection, and the data analysis and how the feedback will be given to the Red Cross Society. The researcher explained in detail the issue of consent form with the help of a translator in the Lozi language; how the selection of 8 participants per group is going to take place. He suggested two groups: one for males only and another for females to allow people to speak freely. The issues of confidentiality, freedom of participations, and freedom of expression and respect of time were discussed. It was said that FGD will take approximately 45 to 60 minutes only and all interviews will be tape recorded. The 30 participants where given a soft drinks and some biscuits. The questions were asked to the group requesting those willing to participate to nominate themselves. Seven male accepted, the invitation and he 8 female from the group decided to participate then all signed the informed consent.

For the males they went outside under a tree. Each group had a moderator, a field assistant to take notes and one tape recorder. The researcher explained to participants in the FGD the process again. The FGD started around 10h55 up to 12h00. At the end of the discussion, the researcher thanked all participants for their time and contribution. After that there was a research team session meeting for 15 minutes to evaluate how the session went and to get the view of the field assistants. In general everything went well as planned.

3.2 Study Design

This exploratory qualitative study was conducted using two methods, focus group discussion of the home-based care givers (who are volunteers from NRCS) to know their views and attitude about home-based care service and a one-to-one interview with clients who are HIV positive accessing medical services at Katima Mulilo hospital at the antiretroviral clinic to explore their knowledge and perception towards home based care services.

3.3 Study setting

The study was conducted in the Caprivi region in Namibia, the North eastern part of Namibia about 1300 Kilometers from Windhoek the capital city and 500 km from the nearest town, which is Rundu with a referral hospital. The Caprivi region is about 400 km long and 80 km wide. It is bordered by 5 countries, namely; Botswana, Angola, Zimbabwe and Zambia contributing to the complexity of the region in terms of cross border activities. (It is the only point where 4 countries meet). It is ravaged by seasonal floods and drought every year compounding the food security situation and Government has to provide drought relief food every year. It has an estimated population of about 90 444 people. The population is very mobile due to the 4 border countries. The FGDs were conducted at Cheshire home. The Cheshire home is a catholic conference centre situated 3 km outskirts of Katima Mulilo town along the Zambezi River.

The Cheshire home has conference facilities and dormitories for accommodation and that was place where all volunteers were accommodated as we conducted the FGDs.

The one-on-one interview was conducted at the ART clinic “Mapilelo clinic” within the Katima Mulilo State Hospital. It is an outpatient clinic open from 8h00-17h00, Monday to Friday manned by 4 doctors, 4 nurses, 1 data clerk, 2 administrative clerks and 2 pharmacists. The clinic caters for all HIV-positive patients and babies from HIV-positive mothers from all over the region. The hospital’s male, female medical wards and the casualty department are open 24 hours with 4 full-time states doctors. Mapilelo home-based care service is managed by Namibia Red Cross Society (NRCS). The caregivers live among the communities in the region.

3.4 Study populations

The first target population group was all HIV-positive clients accessing care at Katima Mulilo ART clinic could have or not benefited from home-based care services. The people living with HIV and AIDS (PLWHA) who participated in the interview were aged between 20-65 years, who on the day of interview they came to refill their medication and others they came for follow up visit.

The second target population was the group of adult caregiver's age between 19- 45 years who have nursed one or more PLWHA in their homes and had received training on HIV/AIDS and home nursing. They are volunteers working for Namibia Red Cross Society (NRCS); home-based care services (HBC).

3.5 Sampling technique

The study participants in the FGD were recruited from the NRCS volunteers attending refresher training at Cheshire home and participants of one-to-one interview where recruited at the Mapilelo clinic as they come to collect their medications or follow up visit. Purposive sampling was used to select the volunteers caregivers using the criteria: (a) a volunteer trained who provided care at least once to a patient or family member infected with HIV and AIDS, (b) a volunteer who had experience of what involved in home-based care, (c) willingness to participate to the discussion at length using a tape-recorder.

There was a series of refresher training organized by the NRCS for duration of 5 days per group in the region. A total number of 30 participants attended the first training, followed by 32 who attended the second training. The participants of the FGDs were purposeful sampled as they attended their training. A total of 15 participants agreed to participate in the study 7 males and 8 females on the first series of workshops and 16 for the second workshop, 8 males and 8 females. A total of 4 FGDs were organized comprising of 31 participants (16 females and 15 males).

For the one-on-one interview, the participants were sampled purposively as they came for their daily follow-up clinic visit, until the saturation of data was reached.

18 patients who had been diagnosed with HIV and AIDS and receiving care and treatment at Katima Mulilo State Hospital ART clinic accepted to participate to the interview. There were ten females and eight males. All these patients were informed by the health care professional and the researcher about the interview when waiting to consult the doctors. The criteria were willingness to be interviewed in length about utilization of home-based care.

3.6 Sample size

On the first day of training, 30 volunteer caregivers were in attendance and the researcher requested participants from the group to volunteer in participating in the research. Two focus group discussions were formed, one for males and another one for females. The FGD consisting of 7 to 8 participants were formed: one group consisted of 7 males while the other consisted of 8 females.

During the second training, this took place at the same venue (Cheshire Home) with 32 volunteers in attendance, whereby 8 males and 24 females were in attendance. The researcher explained to all participants the purpose of the research and how the process of selection and signing of consent forms will be conducted. All Male participants accepted to be part of the FGD and 8 females' participants from the 24 who were present on that training decided on their own to be part of the FGD. The discussion for each group took an hour. For the one-on-one in-depth interviews, 18 people were interviewed. The participants were selected from the PLWHA who came to the ART clinic at Katima Mulilo State Hospital during the period of data collection.

3.7 Data collection and tools

The discussion with caregivers was recorded using a tape-recorder and then transcribed. The participants spoke in their local language as it was difficult for some of them to express themselves in English. A translated questionnaire guide was used to guide the discussion. A

total of four focus group discussions were formed, two FGD were conducted on the first training, one for male and another for female participants in order to get views and opinions of male and female separately during discussion.

The other two FGDs were conducted at the second training and one for male and another one for female participants. The researcher and moderators were always there to guide the discussion. Each group had a field assistant to write non-verbal expressions. The sessions lasted 45-60 minutes depending on the respondent. The researcher participated in all groups' discussions by writing some of opinions given by participants. The participants were served with soft drinks and biscuit but were not paid to participate.

The one-to-one in-depth interviews with patients (KI) who are clients accessing antiretroviral treatment at Katima Mulilo State Hospital "Mapilelo" clinic were held at the Mapilelo clinic using open ended questions. The choice of language of questionnaire to be administered was given to the clients. The English questionnaire was used to clients who feel comfortable in speak English and the translated questionnaire in local language was used on those clients speaking local language.

None-verbal and pertinent point of the discussion were hand-written as the discussions were taking place by field assistant. The researcher was assisted by two field assistants who were oriented on how to facilitate and probe when conducting interview. All tools, including consent forms and questionnaires were translated into the local language by two bilingual people who have been doing similar translation work in the Caprivi region.

3.8 Ethical considerations

The study was approved by the Research and Ethical Publications Committee (REPC) of the School of Public Health and The Medical Ethics and Research Committee (MCREC) of University of Limpopo. Permission was sought from the Permanent Secretary in the Ministry of Health and Social Services in Namibia to conduct the research at Katima Mulilo State Hospital. The Permanent Secretary of the Ministry of Health in conjunction with the Principal Medical Officer of Katima State Hospital granted the permission to conduct the study.

A written/oral informed consent was obtained from all participants after the study goals and objectives were explained to them. Anonymity and confidentiality was maintained throughout the study. With the approval of the Red Cross Regional Manager, the volunteers consented to participate in the study while they were attending the refresher workshops. The informed consent form was also translated into local language (Lozi) by and Mr. Mayamba who works for NRCS and it was checked by an ARV, s clinic Registered nurse, the first and most spoken language of the people residing in the Caprivi Region.

3.9 Validity and reliability

The interviews guide were translated by bilingual local translators from English to local language (Lozi) and the Lozi versions were submitted to a bilingual nurse to read and compare the meaning. These interviews guides were pre-tested to a group of PLWHA and volunteers who were at the research orientation session. Some adjustments were made before the interviews. A trained moderator was used to conduct the FGD and field research assistants were trained to take fields notes for none-verbal expression.

The data was collected with good quality of selectivity to reduce the risk of bias and confounding factors, appropriate sampling procedure, and careful design of instrument to reduce the risk of bias.

Language barriers threatened validity and reliability of the study due to the fact that only a limited number of participants could speak English and therefore an interpreter was used in some instance. The researcher took extra caution by hiring a local professional translator who did work closely when doing the translations to minimize loss of meaning in the data.

CHAPTER 4 – DATA ANALYSIS AND RESULTS

4.1 Introduction

A systematic content analysis approach was used to analyze data, where the participant responses were listed, coded and categorized. Data was categorized into themes and sub-themes and analyzed using content analysis package-NVivo.

4.2 Result

This section presents the view and experience of volunteer caregivers as they perform their daily duty. It also describes the knowledge and perception of the PLWHA towards the home-based care services.

Although all caregivers are trained to provide home-based care service but they require more adapted training to be able to cope with the need of the patients on ART medications as all patients must first go to the hospital to start treatment before being sent home for continuity of care.

The researcher classified the focus groups as: Focus group 1, 2, 3 and 4

- Focus group 1, the first focus group of 8 female participants conducted in the conference hall. All members participated well during the interview. At the beginning participants doubted but after that their feedbacks were interesting and applicable.
- Focus group 2, the first focus group was homogenous with 7 male who were more active and more informative; the discussion was conducted under the tree outside the conference hall.
- Focus group 3, second female focus group conducted on the second training with arrangement of 8 participants.

- Focus group 4, second male focus group conducted on the second training with 8 males.

The researcher classified participants for one-to-one interview as patient 1 to 18. Comprising those who were willing to participate as patients, 8 males and 10 females indicated their participation.

Male patient's numbers, 3, 9,10,12,13,15,17,18

Female patient's numbers, 1,2,4,5,6,7,8,11,14,16

The experience of caregivers and knowledge of PLWHA are discussed below.

4.3 Participant's demographic data

A total of 31 participants (15 males and 16 females) took part in the FGDs sessions. The FGD were conducted with adult men and women of 20 years and above. With regards to educational level, only 10 % people had grade 10 school certificates while the majority of participants were unemployed but doing subsistence farming. They came from different villages of the Caprivi region. For the one-to-one in-depth interviews with key informant, 18 interviews were conducted with males and females participants.

The highest education grade reached among the interviewee's was grade twelve school level, 26 % of the participants to interview were employed with stable jobs. The majority of participants were single while a few were married or staying together with their cohabiting partners.

Study participants were recruited from the Red Cross volunteers at Cheshire Home (center for disabled people) where they were attending 5 days caregivers' refresher training. A total of four Focus Group Discussions were conducted comprising 31 adult participants aged 18 and above. Two FGD were conducted on the first training session and the other two were conducted in the second training.

4.3.1 Understanding and importance of HBC services

Most of caregivers and HIV-positive patients (KI) participants were able to define HBC service as a service which is given in the home environment to patient discharged from the hospital and in need of continuity of care through education, psychosocial, physical support by coaching and mentoring the family in caring for their patients.

Volunteer's response:

"I would like to say that home-based care is the issue that deals with patients who were suppose to take a long time in the hospital now they are taken care by their families, friends, parents, sons and daughters in their specific homes, in which they will help those patients and at the same time doing their usual duties"(FGDs2)

Volunteer's response:

"Our work is very important because it has made us to help patients or families who are ignorant, they did not know what voluntary counseling and testing mean and how HIV/AIDS can spread. But due to the goodness of HBC now people know places where they can go for blood testing and treatment it can be at the hospitals, clinics or new start centre" (FGDs 1.)

"When HBC was not yet introduced all of us were ignorant of where to go for HIV test. From there, the HBC takes care of the patients by directing them on how to take their drugs. It is really needed because without HBC volunteers in the villages, people could die in numbers as some of the patients are our parents who didn't know how to read and write. In addition, our doctors are mostly English speakers so they can just show the patients that take this at this time. So while at home, patients mix up tablets. Therefore since Red Cross introduced HBC, most people now have the knowledge of HIV/AIDS and how to use the tablets" (FGDs 1).

"It is at this time that we also join in to helping and educating those families and friends on how to take care of the patient. It's really a good thing because many patients are not going to stay long in the hospital as we have few beds that can not accommodate many patients and at the same time, we have few nurses who can not attend to many patients"(FGDs 4).

Some of volunteers task have been listed as: Knowing when to refer the cases, where to refer them and sometime escorting the patient to clinics or hospital; provide basic nursing care, emotional support and addressing stigma among other family members and community.

“As HBC givers, our duties are as follows: to give advices to the families who have bedridden people, we encourage people to send patient to the hospital in time and get medical care if the condition of the client is bad” (FGDs 2).

Patient’s response

“When I was very sick for long time my wife abandoned me because her family ask her to do so but HBC givers gives me strength and hope to overcome HIV. They helped me by cooking food, cleaning the house and the yard, fetching water” (patient 3).

“When I was too sick the Red Cross volunteers distribute maize-meal to us, they cleaned me, wash my clothes and plates when all my cousins left me because that time I was passing stool in my pants” (patient 5).

The education and awareness about HIV disease conducted by volunteers has made community to change their risk behavior and reduce government expenditure on health care.

Volunteer’s response

“My opinion is that HBC has brought change in our communities because people were dying too much before the introduction of HBC, information was not available for people to make decisions, but since its introduction, we have seen improvement in the health of our people who are living with the HIV virus” (FGDs 3).

“Our HBC is important because we have seen change and makes the hospital work much easier and also reduce the government expenditures on keeping the sick ones for more than expected. In HBC, families are trained, and that also makes it easier for them to take care of their loved ones when they are sick” (FGDs 3).

4.3.2 Community beneficiaries from HBC services

Many participants from FGDs and interviewees' participants reported that the most people utilizing the service were PLWHA, patients with Tuberculosis and bedridden patient who do not have proper care from relatives. Also Orphans and vulnerable children are beneficiaries including Senior citizens "*Senior citizens are those old age men or women aged above 60 years old*" (FGD 2).

It was further reported that people victims of flood and disabled are beneficiaries too of Red Cross services but not necessarily home-based care service.

Study participants reported the communities' benefits a lot from the service: Reduction of expenditure in transportation, improvement of knowledge and care.

Volunteer's response

"People need the service and are happy with it because it has reduced expenses for the villagers such as spending many days at the hospitals caring for their patients/relatives, traveling long distances just to go to the hospital to collect tablets or to visit a relative in the hospital. Home-based care has totally minimized these expenses as our people are poor. When the patient is discharged, he will get his relatives who already know how to take care of him/her" (FGDs 4).

"The benefits of HBC are a lot; we care, love them, wash them and even carry water for them. We help them in any way that we can" (FGDs 1).

"As HBC volunteers, we also give a very potential help such as water, as you know that it is essential to all living organisms. In villages people they used to draw water out into the streams far into the forest but bedridden people cannot help themselves to go and draw water because they are very weak and need someone to help have free water or clean water, we usually boil the water in order to kill germs and this is another lesson we used to give them all" (FGDs 2).

In addition some participants argue that benefit is reciprocal between volunteers and patients; the more information and education person receive the more he adopt healthy behavior:

“In HBC you also gain knowledge as a volunteer and the patients also get knowledge about their sickness, their drugs and how to prevent themselves from infecting many people. When a person is educated in another way, it is easier for that person to take good care of his own life. Sometimes people are not taught to have good behavior, but in HBC you learn more” (FGDs 1).

Patients express their satisfaction in the way they were treated and supported by HBC volunteers.

Patient’s response

“It was very interesting; they made me to feel strong, because my family was against me” (patient 7).

“the caregivers made me comfortable, feel strong and feel alive” (patient 15).

Patient’ response

“We benefited from Epap, maize-meal, cooking oil; blankets from Red Cross service”

“Volunteers are sometime taking us to hospital when too sick” (patient 4).

4.3.3 Acceptance of the HBC service

The caregiver’s participants in general expressed their satisfaction in terms of how the community appreciates their service: improved their knowledge and understanding of HIV disease but few of participants felt that some members of the community are not willing to be nursed at home.

Volunteer’s response

“I find that the community appreciates our work. We now have light with what we do than before when we started. After receiving a lot of trainings, our work has been easier. We now have improved knowledge and we find that our people have improved and we have been

staying for long with them in HBC and they enjoy being cared for by us. Many people died before HBC was introduced due to HIV and AIDS but now they look good and better” (FGDs 1).

“They all appreciate because if we visit them, they show good welcome and enjoy our services” (FGDs 2).

“People have developed good trust to home-based caregivers because mostly if there is someone with a problem in the community, relatives will come and tell you to come and help them. It may be that someone has an injury or maybe he doesn’t know how to take medicines or another health related issues, they will seek advice from HBC volunteers before rushing to the hospital” (FGDs 1).

“Yes, our services are very worthy because when we call the community for a meeting they do come in number and within the meeting they share very positive ideas which are similar to our answers. They even recommend to us what to do and how they feel comparing to their previous experience. The patients have started to reveal their status to the families and they even bring their problems to us to assist them and that shows trust” (FGDs 3).

Patient’s response

“We need them to give more information about the diseases which troubles people. I am feeling very well and it’s great to be in such a care. The service guides us how we take our tablets and facilitate us to get social support” (patients 2).

“Every one like and need this HBC service, the service is for everyone” (patient 14).

“I never heard anyone complaining about the service and it is bad to complain about the free service, the community needs the support of the service, we need more home based care volunteers” (patient 11).

“I do not think that other people do not like these HBC services” (patient 9).

“We from Bulumba village if we can be visited also and be attached to such services we need the HBC also” (patient 10).

“I do not care about what people might say but what interest me was being nursed at home, it was great, I thank the HBC member for doing and operating such service”(patient 7).

“It is a good service and nothing else” (patient 13).

“We thank them because some patients have lost the family members, so no one is taking care of them and other family members are taking a good example from this, only silly people can be against this, but to my community they are happy with it” (patient 12).

The formation of support group for PLWHA

The PLWHA with their primary family care providers formed some support group which facilitate access to IGAs.

Volunteer’s response

“Ok! Let me start from there, patients accept our services because, although we generally care for these patients, now there are groups we call support groups. These are groups of patients who come together after we personally worked with them first. These are people whom we normally train on positive living, family prevention and care. Patients seem to understand our services as we have been working with them for a long time. But those who are in good health are the one who are in doubt of our services” (FGDs 4).

The service is appreciated by the traditional authority.

“The traditional leaders appreciate the work of HBC, at least now there is reduction in death, because they were losing their people. The community is happy because they even come to ask for advice from us and even ask information of where to go for test” (FGDs 1).

“I have seen in villages people love this program. They say that they would like to meet people who usually train us so that they may also hear from the experts because they usually teach us very well. They also say that they never thought of sharing their problems with strangers but we have taught them that people from different places can help each other in difficult time” (FGDs 1).

Some of respondents noted that they were some people not appreciating their work due to different reasons: some are jealous; others fear to disclose their status and stigmatized.

Volunteer's response

“Among community members, there are those who do not appreciate our services. They come from the village and go to the Regional Red Cross office to report unnecessary things because they are jealous”.

“To add on, I think some people feel jealous because they have not yet learnt something. They do not understand how HBC works” (FGDs 2).

“I think some people are ashamed of knowing their status because they tell us that they don't want to be known that they have the disease. Especially those who claim to be more educated than us caregivers. Some they say that it is us who are encouraging people to have too much sex because of the condoms we distribute” (FGDs 3).

“Men don't show interest in using condoms because they don't know how to use it and what is the benefit of using it. Some men also say that in these condoms there are germs and diseases. Men are difficult to talk to and if possible they should be other home-based caregivers who are men to talk to their fellow men” (FGDs 1).

“Some people fail to understand and when you go to their village they chase us they say “have you seen AIDS here?” (FGDs 3).

“We tried to tell them that we are not here for AIDS only but we talk about all the diseases. Some simply refuse because we are young and that we cannot tell them to use condoms it is an insult” (FGDs 3).

Patient's response

“People will know that you are HIV positive if you are visited by HBC giver with their uniform having a Red Cross” (patient 12).

“We should work hand in hand with one heart to keep the service up, so that everyone could know his status” (patient 1).

“The service must be lifted up of ever together with the Induna's (Traditional chief) of the villages” (patient 8).

“Volunteer caregivers should wear serviettes when working and they should avoid being many when visiting patients not more than 4 members. The volunteers must not wear T-shirt written HBC of Red Cross but they must wear normal clothes” (patient 13).

“Some people don't like the service sometime because other community members may notice

their status by seeing these HBC around them. That can create a lot of gossip from the community” (patient 15).

“Some volunteers have not manners human being remain human being even if is bedridden” (patient 4).

“They start back biting by saying if you see these people from HBC at your place, you are HIV positive” (patient 11).

Volunteer’s response

“ it’s because how we are working; Discrimination is too much when we come to things like food, mosquito net ,bicycles they give their families not to all of us”(FGDs 2).

Patient’s response

“There is a lot of tribalism people gives their relatives and those from the same place of origin or speaking the same language, us from other tribe we do not get anything that is why people do not like to be attached to home-based care” (patient 5).

“HBC volunteers give us simple things but good things they keep for themselves” (patient 3)

” if we had HBC offices we could have been given a bit of money” (patient 10).

“They must have offices to make easier for us to get to them when we need them” (patient 5).

4.3.4 Challenges of volunteers

The FGD’s participants express their satisfaction as more people who were sick are better and valued the training received from the Red Cross to enabled them to undertake their duties with confidence. But their work has many challenges. Stigma plays a role in the type of care patient receive from their own relatives.

The volunteers perceive that their work lacked recognition and it is undervalued by the government.

Volunteer’s response

“We find a problem with the relative of patients in that they are isolating them. When we call these relatives and ask them to look after their patients they always say that it is not them

who use to send the patient to go out without protection therefore they don't care even if that person dies. There is not co-operation between families” (FGDs 1).

“We are traveling long distances on foot and along the way; we are exchanging routes with the wild animals. Coming to work, we have seen problems in the beginning but now they are reduced because people are now have knowledge. The other major problem is that now we are working so hard but we get nothing. If we could be getting something, we could add power to our work” (FGDs 1).

The problem of provision of care arises when there is lack of communication and cooperation between care providers

Volunteer's response

“The main problem is that the channels of communication as per policy are not being followed. The supervisors are now going straight to the care providers – living the facilitators in between. The Facilitators are going straight to the patients – living the Care provider, whereby according to the structure put in place, it should be Patient – care provider – Facilitator – Supervisor – Red Cross office. When the Red Cross goes in the communities, they also go straight to the patients or care providers living the facilitator and supervisor” (FGDs 2).

All the caregivers complained of not being considered for any incentives or any form of payment lately.

“The challenges are a lot, care givers are not rewarded for their efforts and sincere work. Although the Red Cross recognizes us and appreciates the work that we do, there is lots of issues like no incentives for us for the past years that we did the work. We only receive trainings, mosquito nets, other things when they are available” (FGDs 3).

4.3.5 Services supporting PLWHA

Most of participants in the FGD and on the in-depth interview enumerated different support structures supporting PLWHA, Red Cross HBC services, Catholic Action HBC service, buddy program, TCE and new start center.

Patient's response

Buddy program *“which is a group of old PLWHA on ART's medication for more than 6 months trained to provide support to new patients starting medications and experiencing difficulties to take their medicines”* (Patient 10).

“It is a support groups for PLWHA” (patient 11).

Total Control of Epidemic (TCE) *“group which provides house to house HIV prevention education and counseling”* (patient 10).

“Red Cross society providing mosquito nets and blankets to PLWHA and TCE educate family members about facts of HIV/AIDS to comfort patients by advising them” (patient 14).

“Since I started my HIV treatment, I have never seen these offered, I only hear from other people saying that those services are for us” (patient 17).

“Life Ambassadors, they educate people living with HIV/AIDS and non reactive people how to play safe sex” (patient 10).

4.3.6 Suggestion for home -based care services improvement

Some patients (KI) suggested that volunteers should wear serviettes when visiting patients. And other says the nation need this type of program of caring for chronically ill patients and orphans and widows. It was further noted that Volunteers needed more skills for them to give proper care, on how to approach the patients and many, many more things to cover the patients need.

Furthermore an interviewee wish that the HBC service should be established all over the country and permanently as it reduces their transportation cost and makes patient happy when nursed at home.

Patient's response

“Keep it up; we want these services to be all over our country that is the wish of patients” (patient 2).

“Yes it is nice to be nursed at home, because you don t pay transport, they must keep it” (patient 6).

“We want the services to be permanent in the country” (patient 16).

“HBC members must receives more trainings this will help them work better and to keep confidentiality” (patient 12).

“They must employ more people so that the whole country must be covered by HBC members” (patient 8).

CHAPTER 5 – DISCUSSION AND CONCLUSION

5.1 Discussion

The provision of palliative care and terminal care in the home environment to patients is expanding in the era of HIV and AIDS. There is a need to assess factors which may influence the uptake of the home-based care service. The researcher is presenting the findings from the interview with caregivers and HIV positive patients.

The findings show that FGD participants and KI have good understanding and knowledge about home-based care services and that has facilitated the positive attitude towards the home-based care service. The importance of the service has been demonstrated by the patients and volunteers views and this probably explains the reason for its acceptance by the community. Similar findings were seen in Tibebu (2007) study where (91.6 %) of subjects were knowledgeable about home-based care and 88.7 % showed favorable attitude towards home-based care services.

The home care givers group is the most vital resource in relation to HIV/AIDS management in villages as it is the promising group to lead community-led effort to facilitate more effective local response to HIV/AIDS (Campbell *et al*, 2007). The results of this study showed that discrimination is considered as favoritism and tribalism not as rejection due to HIV status. For the participants, discrimination means not to be given what you are entitled to receive as a patient.

The traditional authorities (Induna's) appreciation and understanding of the role of the HBC has made volunteer work easier for accessing people homes that was seen as a sign of acceptance of the service because of their influential position in community decision-making (Williams, 2004) but fear, shyness is a stumbling block to other people to be nursed at home and it is worsened by patients relatives who do not want the service.

The dress code of volunteer was perceived as having a negative impact and interpreted as it discloses people status; however most patients have appreciated the psychosocial, physical

and moral support from the home-based caregivers.

This NRCS service was the only community structure providing nursing support on home-based care to family members close to sick patients. The behavior change campaign and strategies are part of the major activities performed by volunteer caregivers. It has made a change in people decision-making as far as HIV is concerned by giving them more information related to HIV and where to take an HIV test; it has also influenced the improvement of the health of people in the community.

The HBC has made a change in the perception that HIV/AIDS was a death sentence; now due to more knowledge, people are able to access the antiretroviral medication and improve their quality of life. The similar findings were demonstrated in Crook, 2005 study.

The community meeting where HBC volunteers are given the opportunity to discuss issue of HIV is a platform of sharing and learning from each other and clears some of misconceptions. Volunteers perceive that patients do not accept home visits because of stigma and it will alert the community of their status (Beukes, 2005), but in the contrary no patients have raised the same concern.

The general, feeling from patients interviewed is that they appreciate home nursing care compared to hospital care as it is the best method of care; this is contrary to the findings in the Namibia MoHSS HBC Handbook (2001). Lack of remuneration to motivate volunteers can impact negatively in quality of care (UNAIDS, 2000; 2001). The volunteers have expressed their views that they should be part of the Ministry of Health and be remunerated as public servants as they are giving care to PLWHA on behalf of the government. Their other argument is that some of the nurses, jobs have been transferred onto them and hence deserve a decent remuneration. The role of these volunteers has been to counsel, educate and facilitate patients to access the local clinics and hospital and to play a role of mediator between the health facility and the community (Schneider, 2008). An important role of volunteer caregivers is to link patients and their families with different resources like hospitals, nutrition support (Uys & Cameron, 2003).

The government must recognize the importance and role of the HBC service and employ permanent people who will be playing a psychosocial support role at the community level and be paid a salary, as the integration of home-based care in the era of HIV is intended to reduce the economic and human resource pressure, which is a burden to the health care systems especially hospitals (Mokhantso, 2008,). This solution has been difficult for government to incorporate volunteers into the civil service (Schneider, 2008). It has been found that paying a salary to a home-based care volunteer will improve the time for follow-up of patients (Krebs, 2008).

The study showed that there are many challenges facing care givers like lack of transport, walking long distance on foot and without eating, lack of first aids supplied and lack of remuneration to be able to sustain their families. The needs of PLWHA were lack of money to go to hospitals, lack foods and social grants from the government (Campbell et al., 2007). For the PLWHA interviewed, no one mentioned the issue of stigma as a problem for accessing home-based care as other studies shows stigma as a main obstacle for patients to access home-based care (Smith, 2006).

The majority of volunteers are female (Van Graam, 2007) and facing problem to educate men as the culture in the region do not allow women to stand in front of men and discuss sexuality. This will impact negatively on the prevention strategies as the HBC services have more women than men. It is a duty of NGOs and government to put in place strategies for motivating male involvement in this service. The role of home-based care service must change as many people who were nursed in their homes after taking ARV's medicines are feeling better and able to do their daily activities and the focus should be the prevention strategy combined with home care.

The expectation of the community about HBC is very high; people are expecting money and other items from the service as the service is a public generosity program (Stabile, 2006, Ntsunswana, 2006). It should be noted that education level makes people not to be attached to home-based care as the person is more educated in the community as it will be difficult for that person to listen to HIV message from people less educated than him. No participant perceived HIV-infection as being caused by witchcraft (Thomas, 2006). The Ministry of

Health and different NGOs dealing with home-based care service should be encouraged to continuously tailor their training to the current needs of communities.

For the HBC service, the channel of communication between different HBC structures should be followed correctly the undermining of volunteers responsibility by their supervisor as created dissatisfaction and hinder the provision of service. The training of volunteers require to be improved as suggested by other participants especially on methodology of approaching patient home and volunteers should be empowered by building their capacity on pain management and aseptic measures.

5.2 Recommendation

The improvement in people knowledge and attitudes on HIV and AIDS-related issues and their involvement in the community mobilization will facilitate the access of communities to HIV interventions.

There is a great need to intensify and update the training curriculum of volunteer care givers to improve their skills and knowledge. This will also allow them to change their focus in the era of antiretroviral treatment.

The community education to address prevention and reduce stigma should be increased.

The distribution of goods must be conducted with transparency to avoid any accusation of tribalism and nepotism which hinder utilization of the service by the community.

There is need to increase home-based care services coverage in the areas where there are not services at all.

5.3 Conclusion

The good understanding and perception towards HBC led to utilization of service by the community of the Caprivi region.

The acceptance of the service by the community was due to health education and awareness campaign conducted by HBC volunteers. The improvement of community knowledge about HIV and HBC has enhanced the positive attitude toward utilization home-based care service.

There was reduction of stigma in patients interviewed but it was prevailing in people with higher level of education.

While HBC plays a role in relieving the burden of caring duties of government hospital, it requires recognition and support from the government.

The self-report health status to the HBC givers to have access to nutrition support may have played a role in reducing the stigma attached to HIV and increasing the number of people utilizing the HBC service. Studies to identify patients' satisfaction and quality of service provided by caregivers are needed.

As people on ART medication are improving their quality of life, the value of home-based care should focus on assisting people to adhere to their life-long medication, avoid resistance and prevent new infection and as the effect of stigma and discrimination has tremendously reduced, and therefore effort of integration and good collaboration between the government, NGOs and community must be promoted to advance and sustain home-based care.

The success of community mobilization and accessibility depend on how much traditional authority structure involved. Lastly the vision of the service should be oriented to the prevention of HIV infection then to the care of those who are sick.

The improvement of community knowledge about HIV and HBC service has enhanced the positive attitude toward utilization home-based care service that has reduced stigma attached to HIV. Advocacy is required to improve the working condition of volunteer caregiver's home-based care by policy markers.

The collaboration between different stakeholders will advance and sustain the HBC service focusing on prevention of HIV infection.

5.4 Limitation of the study

There were two major limitations in this research study namely: Translation from English to Lozi and vice versa might have prejudiced responses to suit the required answers to each and every response. The sample size prevents to generalize the findings to the entire population of Caprivi or Namibia as it was the opinion and perception of the interviewees.

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APPENDICES

ANNEXURE A1: CONSENT FORM

TITLE: UTILISATION OF HOME BASED CARE SERVICES IN THE CAPRIVI REGION, NAMIBIA.

INVESTIGATOR: KANKU TSHIBOLA NDALAMBO

TELEPHONE 066251400 ext: 473

You are invited to take part in a research study. Before you decide to take part in this study, you need to understand the risk and benefits involved in this study. This consent form provides you with information about the research study. I will be available to answer your questions and for further explanation. If you agree to take part in the research study, you are hereby requested to sign a consent form. It is your decision to take part in the study. You are also free to choose whether or not to take part in the study.

PURPOSE

The purpose of the study is to identify the perception and attitude of people living with HIV/AIDS (PLWHA), their families and the communities toward Home based care services

PROCEDURE

The research will be conducted at Katima Mulilo state hospital. You will be expected to participate in focus group discussion and respond to some of the questions in groups of 8-12 participants where we are all going to give our views on a particular question. This will take you less than 2 hours. If you can not speak English you are free to speak in your local language they will be someone to record and later it will be translated into English for analysis. We are going to record our discussion on the tape recorder and my assistant will be writing everything we discuss.

RIGHT TO WITHDRAW FROM THE STUDY

Your taking part in the study is voluntary. You may decide not to begin with the study or you

are free to withdraw from the study any time.

CONFIDENTIALITY OF RESEARCH RECORDS

The answers and contributions you are you are going to give will be kept private and no one is allow to disclose someone opinion after this research. It will be only me and my supervisor and other NSPH staff who will have access to them. At the end of the study these records will be destroyed.

QUESTIONS

If you have any questions with regard to the study you are free to ask me. In case you have any question after wards, please contact me at the following numbers:

Tel: 066 251400 ext 473(w)

Fax: 066 2535 65

Cell: 0812346736

E-mail: ndalambokanku@hotmail.com, ndalambokanku@yahoo.com,

SIGNATURES

The reason for signing this consent form is to confirm that you have read this consent form that the study has been explained to you, your questions have been answered and you have agreed to take parting the study. You do not give up any of your legal rights by signing this consent form.

Participant (Print Name)

Signature

Date

RESEARCH STATEMENT

I certify that the research has been explained to the above participant by me including the purpose, the procedure and the potential benefits associated with taking part in the study. All questions raised have been answered satisfactory to participants.

Investigator (Print Name)

Signature

Date

ANNEXURE A2 TRANSLATED IN SILOZI

CONSENT FORM: PAMBILI YA TUMELELANO.

TOHO YATABA: SEBELEZO YA PABALELO YA BAKULI MWA MAHAE YA SICABA SA CAPRIVI MWA NAMIBIA

MUBATISI: KANKU TSHIBOLA NDALAMBO

NOMBOLO YA MUHALA: 066 51400 ext 473

Mumemiwa kuba ni kolo ya kuitenga mwa kalulo ya tuto ya patisiso. Pili musu kanga kolo ya kukena mwa patisiso ye, muswanezi kuutwisisa za kozi kapa bunde boo mukona kufumana mwa patisiso ye. Muutwisise kabutungi litaba ze mwa patisiso ye. Na nikaba nimina kualabela kwa lipuzo za mina, ni kumitaluseza za pambili ye kakutala. Hauba mulumela kukena mwa tuto ya patisiso ye, mukakupiwa kunyatele pambili ye ya patisiso ye. Mi sebelezo ye ya kunyatela ibiziwa kuli, kuba ni zibo ni kutwisiso ya pambili ya tuto ya patisiso. Bo ki bona bu iketelo bwa mina bwa kuitenga ni kuba ni kolo mwa tuto ya patisiso ye. Mulukuluhile kukena kapa kusa kena mwa tuto ye ya patisiso.

BUTOKWA

Butokwa bwa patisiso ye kiku batisisa miinelo ni kutwisiso ya mikwa mo bapilela batu baba pila ni kakokwani ka HIV/AIDS, mabasi abona mane kungelela cwalo ni batu bababapotolo hile, ili ktalimisisa za lisebelezo za pabalelo ya bakuli mwa hae.

KAMAISO YA MOKUKABELA

Patisiso ika bela mwa sipatele sesituna sa Katima Mulilo. Mukatokwiwa kuba niku ikopanya ni babanwi mwa litwata zekona ku ba zabatu ba 8 kapa 12 , ilimo lukaba ni kolo ya kufa maikuto aluna kwama lipuzo ze ka buziwa. Mi kalulo ye ikakona kunga ho la kapa mane liholo ze peli. Haiba muikutwa kusa utwisisa hande sikuwa ni kusibulela, mu kuli kukaba ni mutu y kona kutoloka ni kunola litaba kaufela ze ka amboliwa pili lisika hatisezwa kale. Ngambolo kaufela ika hatiswa fa litapa mi mutusi waka yena uka linola ha lunze lu ambola.

LISWANELO ZAMINA HAMUBATA KUZWA MWA PATISISO.

Kuitenga kwa mina mwa patisiso ye ki buipapati ni buitomboli bwa mina. Kamukwa ocwalo mulukuluhile kusaba ni kolo kapa kuzwa mwa ngambolo ye nako kaufela ye muhupula kueza cwalo.

KUNUTU KWAMA PATISISO.

Likalabo mane ni maikuto amina mwa ngambolo ye, lisiala kuba kunutu ye patilwe, mi hakuna ni yomukana ya kona kuba ni kolo ya kutwa kapa kupatulula za ngambolo ye ni kamuta. Kine feela ni yo muhulu waka mane niba beleki ba NSPH ki baba kaba nikolo mwa ngambolo ye. Mi kasamulao wa patisiso ye, mapambili a lipatisiso ze, aka sinywa.

LIPUZO

Haiba muna ni puzo mwa tuto ya patisiso ye, mukona kubuza mulukuluhile kapa haiba mukaba ni lipuzo kasamulao mukona kuni chaela muha fa nombolo yetatama.

NOMBOLO: 066 251400 ext 473/W

Fax 066 253565

Nombolo ya mwalizoho: 0812346736

E-mail; ndalambokanku@hotmail.com, ndalambokanku@yahoo.com.

KUNYATELA

Kunyatela kwa pambili ye kotalusa kuli mubalile ni kuutwisiso za pambili ye, mi mutolokezwi lipuzo kaufela, mi muitumelezi kubani kolo mwa ngambolo ye kabuitomboli. Mi hamusinya sinyi liswanelo za mina ka ku nyatela pambili ye simubuso.

Mabizo amina:

Munya tele

Lizazi kweli ni silimo

LINUSA LA PATISISO

Ni lumela ni kuitama kuli ni tolokezi muipapatiyo ya lumezi kuba ni kolo mwa ngombolo ya patiso ye, ni mutolokezi mulelo kwama libaka la patisiso ye, mi hape nitelokile butokw bwa ku itenga mwa patisiso ye ni ku alaba lipuzo za muipapati kuzwelwafa ngambolo ye iliku kuko lwisa muipapati yo kaufela.

Mabizo a mubatisiis kakutala

Kunyatele

Lizazi kweli ni silimo

ANNEXURE B1

Questionnaires guide for clients one to one interview

Date:

Katima hospital OPD ext

1. From which village do you come from?
2. Can you tell me about Services for supporting PLWHA in your Village?
3. Does you Villages have HBC services?
4. Who use s the services?
5. Can you describe the people who use these services in your village?
6. Why do you think that other people do not prefer to use the HBC services in your village?
7. What is your understanding of HBC services?
8. What kind of services do they offer?
9. What have you seen to be the role of HBC in the community?
10. What are your expectations about Home Care?
11. What did you like about the services?
12. What did you not like about home care service?
13. Have you used or received home based care services before?
- 13.1 What are your feelings about the care you received?
14. What care did you and your family need? Tell me about it?
15. Do you know of any benefits to be nursed at home?
16. What is the opinion of people in the community about people being nursed at home?
17. Do you know of people who don't wan to use HC services in your village?
- 17.1 What do they say are the reasons?
- 17.2 What is your opinion about what they are saying?
- 17.3 What else do you want to discuss about the HC services?

Thank you very much for responding to these questions.

ANNEXURE B2 TRANSLATED IN SILOZI

SEBELEZO YA PABALELO YA BAKULI MWA MAHAЕ YA SICABA SA CAPRIVI MWA NAMIBIA

Lizazi:

Katima Mulilo Hospital OPD extension

1. Muzwa mwa munzi mani?
2. Mwa kona kuni taluseza ka za lituso ze fiwa kwa batu babana ni kakokwani ka HIV/AIDS mwa munzi wa mina?
3. Kikuli mwa munzi wa mina kuna ni lisebelezo za pabalelo ya bakuli mwa mahae?
4. Li sebeliswa ki bomani?
5. Mwa kona kutoloka mufuta wa batu bao baitusisa lisebelezo zeo mwa munzi wa mina?
6. kini hamuhupula kuli batu babamwi mwa munzi wa mina haba tabeli lisebelezo za pabalelo ya ba kuli mwa mahae?
7. Muutwisisa cwani ka za sebelezo ya pabalelo ya bakuli mwa mahae?
8. ki mufuta mani wa lisebelezo obafa?
9. Semukonile kubona mna kuli ki ona musebezi wa pabalelo ya bakuli mwa mahae ki sifi mwa sicaba samina?
10. Zemuakaleza mina kuli ki zona sene swanela mwa pabalelo ye ezahalela mwa mahae ki lifi?
11. Semutabezi mina mwa sebelezo ye yapabalelo ya mwa mahae kisifi?
12. Semusa tabeli mina mwa sebelezo ye ya pabalelo ya mwa mahae ki sifi?
13. maikuto amina kwama pabalelo ye mufumani mina ki afi?
14. ki mufuta mani wa tuso yeo mina ni balubasi lwa mina one mutokwa? Muni bulelele yona?
15. Muziba butokwa mani bwa ku babalelelwa mwa hae ya mina?
16. Maikuto a sicaba sa mukulo wamina kiasi, haba bo na mutu ya kula inge abablelwa ali mwa hae?
17. kuna ni batu bemuziba bao baslati sebelezo ya pabalelo ye kuisebelisa mwa hae ya mina?

17.1 Mi mabaka eba hanela ebata kiafi?

17.2 Maikuto amina ka mabaka efa kiafi?

17.3 Kwanda aze luambozi, sesinwi semubata kueketa kwama sebelezo ye ki sifi?

Luitumezi hahulu ka kwalaba lipuzo ze.

ANNEXURE C1

Questionnaire of Home Based care givers (FGD)

Utilization of home based care services by the community of Caprivi in Namibia

Group type:

Location:

Age average:

1. What are your opinions for the importance of Home Based Care services?
2. As a service provider why do people seek home based care services?
3. In your opinion what is the benefit of HBC for PLWHA?
4. What are the community's views about your service?
5. Does the patient appreciate and know the importance of this service?
6. Are you very comfortable to provide this service in your village?
7. What are the problems you are facing day by day when giving service?
8. What are the challenges of HBC givers in general?
9. Do you know of some people who do not want these services?
10. What are their reasons?
11. What else do you want to discuss about your service?

ANNEXURE C2 TRANSLATED IN SILOZI

KALULO YA C2

LIPUZO ZA BA BABALELI BA MWA MAHAE FOCUS GROPE DISCUSSION

SEBELEZO YA PABALELO YA BAKULI MWA MAHAE YA SICABA SA CAPRIVI MWA NAMIBIA

Mufuta wa sikwata:

Sibaka/munzi:

Lilimo:

1. Maikutoamina kwama butokwa bwa sebelezo ya bakuli mwa mahae ki afi?
2. Mina kakuba ba babaleli ba mwa mahae, ki buto kwa mani bo batu babata mwa sebelezo ye ya mwa mahae?
3. Kamaikuto amina batuba bapila ni kakokwani ka HIV/AIDS ba fumanani mwa pabalelo ye?
4. Sicaba semu pila ni sona balini kwa sebelezo ye?
5. Kikuli bakuli balumba ni kuitumelela sebelezo ye kuli ibutokwa?
6. kana kikuli mwa itukwa hande mwa musebezi o ha munze muueza mwa sicaba?
7. kimatata mani ni ona kazazi mwa musezi o?
8. Matata afumaheha mwa musebezi o kaufela kouya kouya ko ukuwa ki afi?
9. Kana kikuli semu lemuhile batu baba salati sebelezo ye mwa sicaba?
10. Mi bao basalati sebelezo ye, bafa mabaka mani?
11. Sesimwi semubata kubulela kwama mu sebezi wa mina ki sifi?

Luitumezi hahulu ka kwalaba lipuzo ze

RESEARCH CERTIFICATION

UNIVERSITY OF LIMPOPO
Medunsa Campus



MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

P O Medunsa
Medunsa
0204
SOUTH AFRICA

MEETING: 05/2009

Tel: 012 - 521 4000

PROJECT NUMBER: MREC/PH/86/2008: PG

Fax: 012 - 560 0086

PROJECT :

Title: Utilisation of home based care services by the community of Caprivi in Namibia

Researcher: Dr K Tshibola Ndalamo
Supervisor: M Mokgatle-Nthabu
Department: Social and Behavioural Health Sciences
School: Public Health
Degree: MPH

DECISION OF THE COMMITTEE:

MREC approved the project.

DATE: June 09, 2009


PROF GA OGUNBANJO
DIRECTOR: RESEARCH & CHAIRPERSON MREC



Note:

- i) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
- ii) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

PERMISSION TO CONDUCT FOCUS GROUP DISCUSSION



FACULTY OF HEALTH SCIENCES, SCHOOL OF PUBLIC HEALTH STUDENT RESEARCH PROJECT MANAGEMENT DATA COLLECTION CONFIRMATION SHEET

1. Researcher declaration

Name of Researcher **Kanku Tshibola Ndalambo**
 Title of study: **UTILISATION OF HOME BASED CARE SERVICES BY THE COMMUNITY OF CAPRIVI IN NAMIBIA**

Research project Number **MREC/PH/86/2008**
 Period of data collection: Initiated..... **25/08/08**..... Completed..... **10/09/08**.....

I hereby declare that I collected data according to the specifications of the approved proposal.
 Signed:..... *[Signature]*

2. Research site and activities

Name of organization/institution

Type of organization/institution (mark with an X)				
Industry	Health facility	Educational institution	NGO	Other (specify)
			X	

Town/Village (name)	Country
Katima Mulilo	Namibia

Main data collection activities (sign against all applicable)			
Interviews	Focus groups	Record reviews	Self-administered questionnaire
	X		

Other people involved in data collection ... **Mr Mayamba, Mr Josephat Muliunda, Mr Moses Malumo and Carel syambango**

I, **Ms Polly Helmut** being the **Red Cross regional Manager Caprivi region**..... (position) of the above organization/institution, hereby confirm that the researcher named above collected data as indicated

Signature..... *[Signature]* Date: **12 August 2008**

Contact details of organization/institution

Postal/Physical address ... **Po box:2289 Ngweze/Trans Caprivi Highway**...
 Telephone... **+264 66253415**..... Facsimile... **+264 66 252641**.
 Email ... **pollyhelmut@yaoo.com**.....

Official stamp of organization
Namibia Red Cross Society
P.O. Box 2289
Ngweze
Katima Mulilo
 Tel: 066-253 415 Fax 066-252 641

PREMISSION TO CONDUCT ONE TO ONE INTERVIEW



FACULTY OF HEALTH SCIENCES, SCHOOL OF PUBLIC HEALTH STUDENT RESEARCH PROJECT MANAGEMENT DATA COLLECTION CONFIRMATION SHEET

1. Researcher declaration

Name of Researcher **Kanku Tshibola Ndalambo**
 Title of study: **UTILISATION OF HOME BASED CARE SERVICES BY THE COMMUNITY OF CAPRIVI IN NAMIBIA.**
 Research project Number: MREC/PH/86/2008; PG
 Period of data collection: Initiated. 15/11/08.....Completed... 15/01/09.....

I hereby declare that I collected data according to the specifications of the approved proposal.
 Signed:.....

2. Research site and activities

Name of organization/institution: **Ministry of Health Katima Mulilo State Hospital (Principal medical office).**

Type of organization/institution (mark with an X)				
Industry	Health facility X	Educational institution	NGO	Other (specify)

Town/Village (name) Katima Mulilo	Country Namibia
--------------------------------------	--------------------

Main data collection activities (sign against all applicable)			
Interviews X	Focus groups	Record reviews	Self-administered questionnaire

Other people involved in data collection ... Mr Mayamba, Mr Josephat, Mr Moses Malumo.....

I, **Dr P Bwalya** being the ... **Principal Medical officer Katima State Hospital**
 (position) of the above organization/institution, hereby confirm that the researcher named above collected data as indicated.
 Signature Date: 10 November 2008

Contact details of organization/institution

Postal/Physical address ... Pobox: 1081 Ngweze/ Katima Mulilo Town centre.....
 Telephone: +264 66 251400... Facsimile: +264 66 252605

