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**Determinants of home based care services provision for the  
people living with HIV/AIDS: A case study of Hope (“Tumaini”)  
Home Based Care Programme in Tanzania**

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## **Declaration**

I, **Paul Mahunga** hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicated) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree at this or any other university.

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Date: 31 March, 2012

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## **LIST OF ABBREVIATIONS/KEY WORDS**

ARV	Antiretroviral (drugs)
CBO	Community based organization
CTC	Care and Treatment Clinic
FBO	Faith based organization
FHI	Family Health International
GDP	Gross Domestic Product
HBC	Home-Based Care
IGAs	Income generating activities
MOH	Ministry of Health
MDGs	Millennium development goals
NGO	Non-governmental Organization
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
PLHIV	People Living with HIV/AIDS
PEPFAR	President's Emergency Plan for AIDS Relief
PMTCT	Prevention of Mother to Child Transmission
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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## **Abstract**

The higher increase in the number of HIV/AIDS patients in the country has necessitated the expansion of Home Based Care (HBC) programmes and has called for the need to strengthen the HBC services in Tanzania. Since scaling up of HBC services is fundamental and the resources dedicated into HBC programs are supposed to be utilized efficiently, the factors hindering the provision of HBC services should be known and resolved.

A cross sectional study was applied in studying the factors that influence the provision of HBC services and a quantitative method of data collection and analysis was used. A sample of 8 civil society organisations out of 23 carrying out HBC activities under “Hope” HBC program were selected, representing organizations from rural and peri urban areas. The study collected information from organizations leaders and the community volunteers providing HBC services from the sampled organizations. A systematic sample was done to select the volunteers and in total the study interviewed 8 Organization leaders and 113 Volunteers from the sampled eight organizations.

The study concluded that there are internal and external organization factors and HBC volunteers’ factors that hinder HBC services provision in the country. The major internal organization factors found include inadequate supply of HBC kits, lack of organizations capacity to solicit funds for the program and the lack of strategies to motivate the community volunteers. The external organization factors found include unavailability of referral points for different services, distance and cost to get to the facilities results into poor access to HBC services. Other factors found are the low levels of donor funding, cultural factors such as traditional medicines and believes in witchcraft, self stigma and the lack of community support and male involvement, all these hinder access to home based care services. The volunteer factors found are inadequate motivation to volunteers, workload and lack of refresher training to volunteers.

The study recommends home based care stakeholders to come up with appropriate policies and plans that will promote people living with HIV and AIDs (PLHIV) to have more access to home based care and other health care services. This includes strategies that can counter stigma and discrimination and also researching on the cultural factors hindering care, treatment and prevention efforts and how to tackle the hindrances.

Poverty reduction programs should collaborate with the HBC stakeholders and join force in reducing poverty by strengthening PLHIV households’ income generating activities.

There has to be some deliberate efforts to build the capacity of the HBC organizations in soliciting funds and in mobilizing the community and men to participate and contribute towards home based care activities. Also the HBC volunteers should be motivated through provision of working materials, transport support, supportive supervision refresher training and social support.

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## **Chapter one**

### **Introduction**

*The chapter lays down the background introduction of the study, the problem statement, significance of the study and the objectives of the study.*

#### **1.1 Introduction**

Tanzania joined the rest of the countries which signed the millennium development goals (MDGS) in year 2000 and among the eight MDGs adopted by the country include combating HIV/AIDS, malaria, and other diseases. Promotion and scaling up of home based care services is fundamental in meeting this MDG which addresses the vulnerability to HIV/AIDS and other related threats including malaria aiming at promoting the well being and quality of life of individuals (AFRODAD 2005).

Tanzania is taking the problem of HIV/AIDS as one of the areas of high priority in the health care plans and in 2003 the country endorsed the national HIV/AIDS care and treatment plan. To guide home based care (HBC) activities, the country also endorsed the Guideline for Home based care services in Tanzania in 1999 (MOH 1999).

Provision of home based care to people living with HIV/AIDS is one of the strategy in the national care and treatment plan, the strategy that aim at contributing in strengthening social support for care and treatment of People Living with HIV/AIDS (PLHIV) in Tanzania through home-based care, local support groups, and treatment partners (MOH 2003)

Home based care is any form of care provided to chronically ill people in their homes so that they can live the best possible good quality life. Home based care activities take the advantage of community and family support in providing the many services required by the chronically ill patients. Home based care is the most desired alternative in assisting the over burdened health facilities (WHO 2000)

## 1.2 Demographics

The United Republic of Tanzania is one of the East African countries estimated to have an area of 364,898 sq m. The population of Tanzania Mainland is estimated at 38 million (<http://www.library.uu.nl/wesp/populstat/populhome.html>). 58% of the Tanzanians are living below the poverty line with an income of less than 1 USD a day (<http://mdgs.un.org/unsd/mdg.data.aspx>). The country is one of the poorest countries in the world with low income and expenditure. The social economic indicators show a high mortality and morbidity, low education level and poor nutritional status (AFRODAD 2005). The per capita public health spending was US\$ 6 in the year 2001 and the government plan was to increase it to 9 USD in the following 3 years and thereafter to 12 USD by year 2004 (MOH 2003).

First incidence of HIV/AIDS was reported in 1981 and since then it has claimed the lives of more than 25 million people worldwide, it is also believed that more than 40 million people are living with HIV/AIDS today, including 2.3 million children. 95% of people living with HIV/AIDS are in low and middle-income countries and since 1995 the number of infected people has doubled worldwide. Each year in Africa about 2.5 million people die from HIV/AIDS and the impact of the disease is enormous including declining in the life expectancy in African continent (Sepulveda 2003).

Tanzania just like any other sub Saharan African country has not been spared from the HIV/AIDS scourge. HIV/AIDS is one of the biggest problems facing Tanzania as far as social and health issues are concerned. The country has more than 1.6 million people infected with HIV and 7% of adults 15-59 are infected by HIV (Anika 2007)

Among the women who attended the antenatal care clinic facilities in the country in 2002, 9.6% were HIV positive. In 1999 the average life expectancy at birth was estimated to be 49 and 47 years for female and male respectively but it is said to have declined further (UNAIDS 2004).

The impacts of HIV/AIDS in the country are many of which has led the country to declare this problem as a national disaster. The reports from TACAIDS, NBS & ORC Macro 2005 and UNAIDS 2006 indicate that the pandemic has contributed to the decline of some development indicators in the country.

These include the decline in life expectancy among the people in the country, gross domestic product and productivity, increased infant and child mortality, poverty and household dependency ratio.

The mortality rates has increased leading to more orphans and an indicators survey conducted in the country in 2003-2004 shows that children under 18 who have lost one or both parents stands at 11%, and the country has more than 1.1 millions children orphaned by HIV/AIDS (TACAIDS, NBS & ORC Macro 2005).

Tanzania is resorting to the provision of home based care services due to limited resources for caring the people living with HIV/AIDS both at the communities and health facilities. The health care systems are overburdened and therefore the need to consider HBC as an alternative towards providing services to people living with HIV and AIDS. HBC will reduce caring cost, which is in terms of households caring costs which include transport and medical cost and work foregone while caring at the hospital. Another major advantage of HBC is that it promotes the access to HBC related services hence a holistic access to different needs of the PLHIV that could be met while ensuring the availability of quality services. HBC also strives to build community ownership of the health related problems in the community and it reduces patients' isolation since it creates more time with their family members and hence more time of receiving care. HBC builds the capacity of home care giver as HBC volunteers always strives to educate the family members and give them knowledge and skills on chronically ill patients care (MOH 1999)

### **1.3 Models of home based care in Tanzania**

Different types of home-based care models exist depending on the country care and treatment policy. Three key models exist (<http://www.fhi.org/NR/rdonlyres>); the first one is the facility based or outreach care where health care facility such as a hospital sends health care workers on time to time bases to visit the homes with people living with HIV/AIDS mostly providing nursing and medical care and occasionally psychosocial support.

The second model is the community based home care where the pillars of the services are the community volunteers who receive trainings on home based care. Volunteers are supported with working materials including HBC kits. Community volunteers visit the families with patients where they provide basic nursing care, emotional support and spiritual support to the patients and the families.

In this model community home based care volunteers also provide HIV/AIDS education to the families of which gives the families confidence in caring for their patients and in reducing stigma and discrimination. Community home based care volunteers also ensure patients are referred for appropriate services when needed; the model enables building of networks with other service providers. The major challenge of this model is maintaining and supporting the volunteers.

The third model of home based care is the community day care where periodically home based care programs practising the second model assemble the patients from one area at one point and provide them with HBC related services such as symptom management, drugs, recreation and counselling. One of the advantages of this model is that it gives the volunteers some break and relief as they get an opportunity to interact with the program staff and air out some of their problems.

#### **The Tumaini-‘Hope’ Home based care program.**

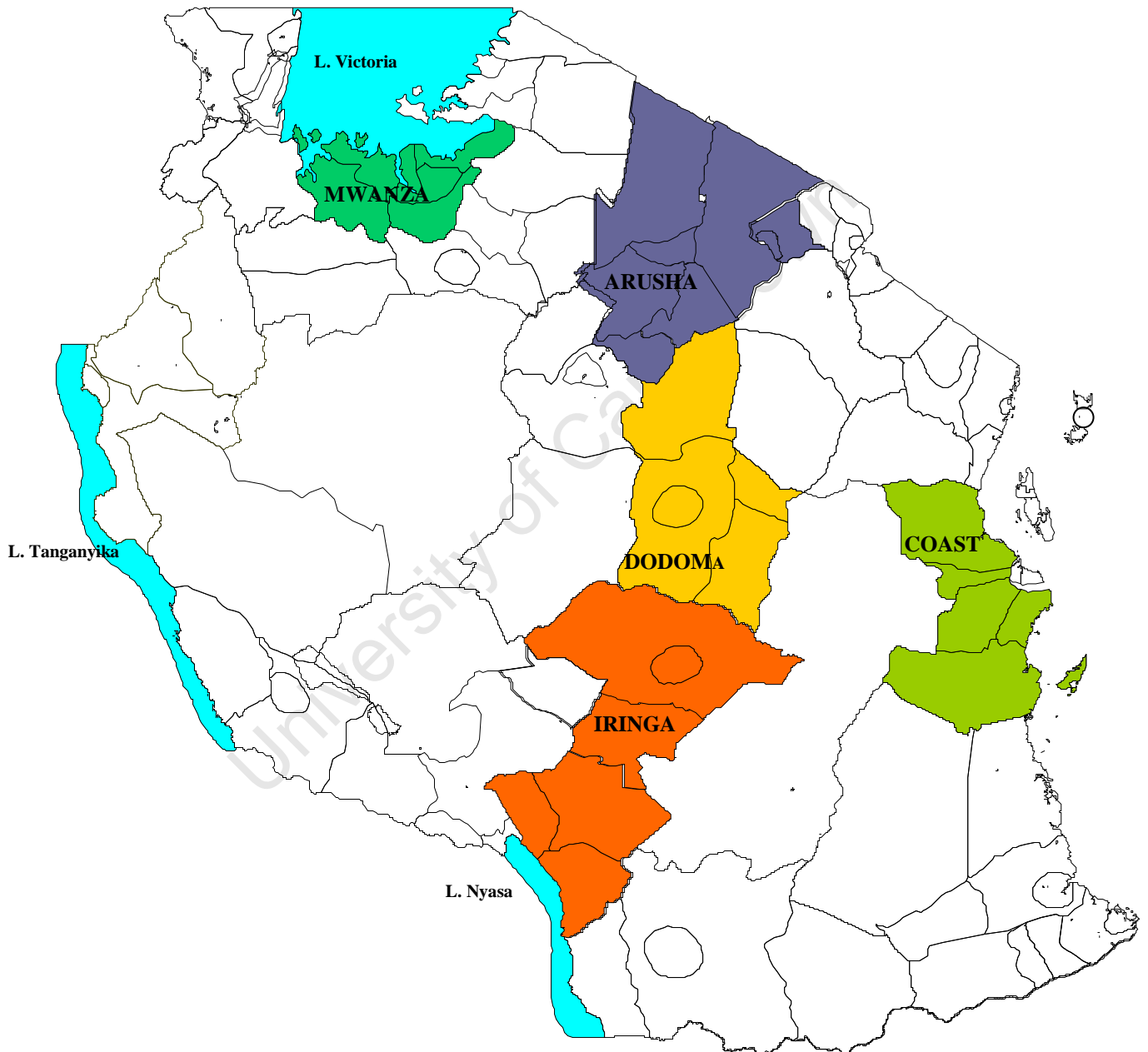
The study area is Tumaini program which follows the second model of HBC but without day care sessions. At the lower levels of the community the program is run by civil society organizations which are Faith Based Organizations (FBOs), Community Based Organizations (CBOs) and Non-Governmental Organizations (NGOs). The program was initiated in early 2004 and is funded by the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). The program is headed by an organizational alliance initially headed by CARE International, with technical partners Family Health International, Heifer Project International, Health Scope Tanzania, Muhimbili University College of Health Sciences, and Centre for Counselling, Nutrition and Health Care. It is a community home based care which aims at working hand in hand with the community in providing the services to the clients. The advantages of this model of HBC stems from the concept of building referrals and networks with other service providers so as to ensure early access to and communication between services in order to meet the many needs of the chronically ill patients and their households. Its focus is to strengthen referrals and the coordination of services between service providers such as health care facility and the community.

Up to 2006 Tumaini program was supporting twenty-three local organisation or sub-grantees in providing home-based care for families affected by HIV and AIDS in five regions in Tanzania namely Arusha, Dodoma, Iringa, Mwanza and Coast.

“Tumaini” is following the model of private HBC run by civil society organizations and it is the most predominant model of HBC being promoted in the country.

**Figure 1: Tanzania map indicating Tumaini HBC program working areas**

The shaded regions of Arusha, Dodoma, Coast, Iringa and Mwanza)



#### **1.4 Problem statement and the rationale for the study**

The higher increase in the number of HIV/AIDS patients in the country has necessitated the expansion of HBC programmes and has called for the need to strengthen the HBC services. Formalized home based care is a new area in the country but the plan is to scale up these services as one of the strategies to meet the over burdened health care facilities and fight other HIV/AIDS impacts.

Since scaling up of HBC is fundamental and the resources dedicated into HBC programs are supposed to be utilized efficiently, the barriers towards HBC should be resolved. Since there is no known study conducted in the country on this aspect then there is a great need to conduct a related study as unknowingly there could be some factors hindering the provision of these services. The information on the factors that hinders the provision of HBC services is important to HBC stakeholders including the Ministry of Health, the donor and the organizations implementing HBC. The information from the study is expected to guide the planning and the policy formulation.

Accesses to health care services differ between rural and urban settings as indicated by Develay et al (1996) and therefore it is important to find out if it is the same case with home based care services provision so that appropriate measures can be considered. Most of the researchers have studied the shortcomings of HBC from the demand side such as the patients and their household care givers and less has been studied on the factors that influence the provision of HBC services and particularly from the provider's side (Akintola 2004; Sepulveda et al, 2003). This indicates that health care stakeholders particularly those who deal with HBC in one way or another may be lacking knowledge on the possible factors that could be hindering the provision of home based care services. This has called for the need to gather some information on the subject matter so as to promote the provision of HBC services. This study then intends to underline the factors that hinder HBC services provision.

### **1.5. Aim and objectives**

The aim of the study is to examine the major determinant factors that influence the provision of home based care services in the Tanzanian context.

#### **1.5.1 Specific Objectives:**

- To determine the internal and external organization factors and HBC providers (Volunteers) factors that influences the provision of HBC services.
- To explore on availability of HBC services between rural and peri urban settings.
- Based on the study findings, to provide recommendation that will enable the policy makers and other HBC stakeholders to enhance HBC services provision in the country.

#### **1.5.2 Hypothesis:**

The study hypothesised that there is a difference in the levels of home based care services provision between rural and peri urban areas.

## **Chapter two**

### **Literature review**

*The chapter outlines the literature review with regard to home based care services provision specifically in relation to the factors hindering the provision of HBC services. It also provides an overview of the guiding principles for successful HBC service of which has led into the development of the conceptual frame work for the study.*

#### **2.1 The guiding principles of successful HBC services**

The aim of home based care is to provide services that improve the quality of care for chronically ill patients and these services should be provided at the health facilities and at patients homes (MOH 2005).

Tanzania Ministry of Health (MOH 2005) laid down some guiding principles for successful HBC services. The first guiding principle of successful HBC services is that these services should be comprehensive or holistic, that the services to PLHIV should include medical care, counselling and psychosocial support, spiritual care, material and social support such as welfare, legal advice and referrals.

The second principle is that there should be a continuation and linkages of these services, scholars refer to this principle as a continuum of care (MOH 2005; FHI 2004). The continuum of care means linking all elements of services that are needed and make them available to PLHIV. The services to be linked are those from the health and other services, social support and institution or programmes that provide needs to PLHIV and their families. In this manner, the health facilities should not shift their roles into the community but rather to support the provision of the same services to PLHIV while at their homes (Eric van Praag and Daniel Tarantola 2006). This principle calls for the need to build referral systems that link the patients with the services that are provided at the facilities or institutions, the community and their homes. The benefits of linking the patients to different services are many, according to Stuart L et al (2005) referral network enables PLHIV and their caregivers to achieve a higher quality of life and to facilitate participation on the decisions affecting their lives and to promote social recognition.

The third principle advocates for the need to integrate HIV prevention programs into HBC activities. The prevention programs may include prevention of mother to child (PMTCT), condoms provision and information education communication materials on prevention.

The Fourth principle is to promote the reduction of stigma and discrimination among the patients and their families so as to bring about equity in accessing the services.

The last principle is that the HBC programmes should be owned by the community so as to bring about sustainability. The community can participate in HBC activities by providing moral support, materials, other contributions and time to care for the needy patients.

From the HBC guiding principles we can identify three levels of actors or stakeholders that can influence the provision of HBC services.

The first level is the organizations providing the HBC services, the second level include stakeholders that lay outside the organizations providing HBC services but they have some influence on HBC services provision, they include the donor, Ministry of Health (MOH), government facilities where PLHIV can be referred for different health care services such as VCT, care and treatment clinics (CTC), clinics, dispensaries and hospitals. Other stakeholders outside HBC organizations are the other institutions or programmes that compliment HBC services they include prevention programs, referral points where PLHIV can be referred for support services such as nutritional, income or economic strengthening and psychosocial support.

The last level is the community including the community volunteers who are the front line cadre in the provision of HBC services.

## **2.2 HBC Services**

The aim of the HBC services is to improve the quality of care for chronically ill patients within the health facilities and at their homes, so it's a two way kind of care; care at home and from other facilities. Since people living with HIV/AIDS and the households affected have different needs which change over time as infection progresses to illness and advanced disease, HBC programmes are developed as in response to these needs and demands (MOH 2005; Ntozi 1997).

Tanzania Ministry of Health (MOH 2005) advocates for the following services to be included in the HBC package

- Prevention awareness raising, community mobilization, VCT.
- Advocacy to fight stigma
- Nursing care
- Referral to health facility for further care of opportunistic infections, monitoring of HIV progression and to other social economic services.
- Counselling spiritual and emotional support.
- Transferring skills to home care givers in areas such as basic nursing care, hygiene, positive living, nutrition, emotional support, infection prevention, referral and networking.
- Social support information and referral to support groups and material assistance

According to (MOH 2005) a minimum package of HBC services is the essential set of activities and resources (equipment, drugs/HBC kits, supplies and personnel) that are important in providing the services to the chronically ill patient at a minimum required level of service.

HBC services needs to go beyond services from the health facilities, Akintola (2004) identified four stresses that PLHIV and families affected by HIV/AIDs undergo; physical, economic, social, emotional and psychological stresses.

WHO (2000) and Lindsey (2002) pointed out that most of the chronically ill patients would rather be cared for at home and that effective home care improves the quality of life for chronically ill people and their family caregivers. Therefore HBC programs should strive to provide hope through good quality and appropriate care that helps patients and families maintain their livelihood and have the best possible quality of life. A well-functioning HBC program provides a range of services to persons with chronic illnesses from a health care facility to the home environment. For sustainability the services must be linked and integrated into the existing district health care delivery systems and plans (FHI 2004, MOH 2005).

A study on end of life experience found out that the most need of the terminally ill patients were the relief of pain, access to affordable drugs and financial support. Other needs include the relief of opportunistic infections, social, emotional and spiritual support (Sepulveda et al 2003). The same study found out that most of the deaths from the AIDS patients are accompanied by pains and other sufferings that could be avoided if there were proper home based care services.

### **2.3 Internal organization factors**

Internal organization factors that determine the organization ability in providing HBC services are the factors that are within the organizations and they can be controlled or influenced by the organisation. The presumed factors may include the capacity of the organization in terms of resources pooling particularly funds, staff retention, motivation and support to staff particularly volunteers and program monitoring.

Most of the HBC activities in Africa were established by church organizations or some individuals for example retired nurses. Most of the HBC initiatives are facing the challenges of access to resources both financial and human resources which have made it difficult to expand the services (White J. and Robinson E. 2000). Other studies of home-based care (Adebayo et al 2004 and McCreary et al 2004) have indicated the problem of poor funding of HBC programs and that the programs have been left to the NGOs to run. Financial challenge translates into little funding for running the HBC activities including transport to the field, paying salaries for the staff and stipends for the volunteers also for purchasing working materials such as HBC kits for the volunteers. The same study also showed that the NGOs lack infrastructures and capacity to run the programs.

The contribution of the volunteers in providing HBC services is of great paramount, without volunteers efforts the patients home caring could not be delivered. However for the volunteers to perform, a continue support in terms of working materials, trainings, field supervision and emotional support is highly needed. As part of de-stressing the volunteers, regular meeting can be utilized to resolve some of the problems faced by the volunteers. It is also noted that volunteers are motivated by the benefits they bring to the patients, their relatives and to the program as a whole.

Volunteers also benefit in the course of providing the services when they network and build friendship with other volunteers and the program staff (Fisher RA and MCDaid P 1996)

#### **2.4 External organization factors**

External organization factors are the issues which lie outside the organizations providing HBC, they cannot be controlled by the HBC organizations but they influence the performance of the organizations in providing HBC services. The presumed factors in this study include availability of referral points and their access, support services such as income, nutritional, legal support and emotional support. Other external factors are availability of HIV preventions programs, community and male involvement, stigma and discrimination reduction, support and supervision from government health facility supervisors, cultural factors and the level of donor funding.

According to the Tanzania Ministry of Health (MOH 2005), participation of the patients and their home carers is important and the male involvement is encouraged. Their participation include, care for the family carers, health care for children, orphans and vulnerable children (OVC) including sick children, record and reporting system and prevention interventions for example prevention of mother to child (PMTCT).

Kavuma et al (2004) pointed out lack of male support and involvement as one of the set back towards the provision of HBC services. It was suggested that men should be involved in implementation of home based activities since they are the major partners in the households and therefore programs should promote male involvement. Men should be in the provision of HBC services in their homes since they are the decision makers on various issues including health care services seeking. In Senegal a study indicated that 50% of the decisions on the type of health care services to be sought by women are decided by men (Post 1997)

Transport problems in terms of poor roads and cost involved hinders the provision of HBC services. A study by Campbell (2005) showed that poor infrastructures such as roads being one of the factors hindering the people living with HIV/AIDS from accessing different HBC related services.

The same study showed that some patients were found to have missed their appointments at the clinic and hospital for follow up visits and medication or to access welfare services such as food and grants as the result of lack of transport and impassable roads. Also in some areas patients were found to be walking far distances in order to access public transport and in some instances carers are sometimes forced to carry patients on their backs or push them on the wheelbarrow and some do not make it to the destination. Mobile clinics should have been considered as a solution for some areas where health care facilities are not accessible but even in the areas where they have set up this service it is still not reliable as it was reported in the same study that the mobile clinic was visiting the place once a month and when it rains it does not visit and hence those who cannot access medical care resort to traditional healers.

Stigma and denial about the existence of HIV/AIDS is reported to be one of the factors hindering the HBC provision. Campbell (2005) reported that in some cases home caregivers or the volunteer are not aware of what their patients are suffering from putting the care givers at risk. Fear to disclose HIV status puts the patients in many obstacles including taking up ARV or the care giver to monitor adherence of the drugs. A study by Mann (1989) revealed that stigma and discrimination is an epidemic that needs attention just as HIV/AIDS epidemic itself.

Stigma and discrimination as an epidemic goes beyond the medical to the social and it includes the blame, denial and stigmatisation including self-stigma which is rampant in all the communities affected by HIV/AIDs. In Tanzania, Lwihula et al (1993) found that AIDS patients in one hospital were isolated into separate wards but the patients resisted such isolation claiming that it would reveal their HIV status. It was further remarked that the patients who were aware of this isolation never wanted to be admitted in this hospital of which denies them health care services. A study conducted in Ghana by Awusabo (1995) reported that stigma and discrimination make the patients who receive sero positive HIV test results to conclude that it is the end of their lives. The patients were revealing self-stigmatisation since they also conclude that they are stigmatised and discriminated by the community including relatives and spouses.

Stigma and discrimination to HIV/AIDs patients has been documented as one of the factors hindering home based care activities. Stigma accelerates stresses to patients leading them to isolate themselves both physically and emotionally from social interactions.

The society, friends, family members, health care facilities and others stigmatise the HIV/AIDS patients of which puts them into fear, depression, grief, shame, denial, anger and guilt.

This isolate patients from the society leading to a number of losses including loss of properties, jobs and failure to attend to different health care services (Alta Van Dyk 1999).

Cultural believes could also be hindering the provision of home based care, a comparative research conducted in Uganda and South Africa showed that home based care programs reflects gender inequality due to traditional role of women as most of the care givers were found to be women and girls (Akintola 2004). Lwihula et al (1993) pointed out that witchcraft believes and the use of traditional medicine has been practised in most of the African countries for many years, it forms another kind of health care in most of the African countries and most of the AIDS patients are turning their faith into traditional healers. This is simply because some of the traditional healers are claiming to be able to cure the disease

Households income status is a major determinant for the PLHIV to access and acquire different required services however the cost and burden of caring for the patients which include cost incurred to take care the patients and the time waste makes the families affected by HIV more impoverished, it is even worse when the patient is the bread winner in the household ([http://www.tanzania.go.tz/hiv\\_aids.htm](http://www.tanzania.go.tz/hiv_aids.htm)). Effective home based care programs should include poverty alleviation strategies such as small income generation activities in addressing the issues of income in the families receiving HBC service, otherwise the medical trap of health care will continue within these families (Ogotu 2005).

The need for economic strengthening is further shown by the Tanzania HIV&AIDS Indicator Survey (THIS) (2003/4) which reported that out of the 355 chronically ill patients aged between 18 – 59 who were very ill for 3 or more months during the 12 months before the survey, only 11.6% lived in households which had received material or practical support (<http://www.unrisd.org/TanzaniaRR4.Pdf>). The survey revealed further that support is more common for adults living in urban areas than rural areas.

In Kagera, Tanzania women aged between 15 to 39 were found having higher probability of dying from AIDS than other causes of death of which confirms that adults are dying from HIV/AIDS while in their most productive ages hence leading to poor production in their households (Ainsworth and Semali 1998). According to Campbell (2005) home based care volunteers claimed that most of the patients do not have access to regular or nutritious meals hence they are reluctant to take medications on an empty stomach. The same study indicated that public sector support is very limited in terms of their role, when HIV/AIDS grant require access to computer the patients have to travel 50 km, a trip that most of them cannot afford either health care facilities are placed in the neighbouring town and they are staffed by nursing staff with no doctors.

According to Ritzenthaler (2005) the many benefits of building referrals and linkages with other HBC stakeholders include ensuring early access to HBC related services and communication between service points in order to meet the many needs of the patients and their households. Home-based care needs the efforts of all the stakeholders since better health is a set of social and economic efforts of the country. There is no single entity that can provide all the range of services needed by the people in need of HBC related services then collaboration between these stakeholders is of a great paramount. Referrals strengthens the coordination of services between services providers and the community, it reduces the duplication of services and assists the clients in adhering to drugs and other related health care appointments. It is further advised that referrals should bear a coordination focal point, tracking system and documentation and reporting system. Inability to access the ARVs treatment has been mentioned as one of the factors causing patients not to adhere to these drugs. This is because public ARVs programs are new in most of the developing countries and in most cases they are now starting to scale up in these countries so as to cover the majority (FHI 2004)

Voluntary counselling and testing services are important in the care and support for the people living with HIV/AIDS since identified patients from the VCT can be linked with home based care programs after being counselled and tested. According to (Alta Van Dyk, 1999) counselling promotes motivation to the individual being counselled and brings about positive changes and therefore advice on the possible care to the patients. This in turn assists individual patients to accept information on their health and its impact.

While HIV/AIDS services are much more concentrated in the urban and semi urban areas the higher interaction of the people between rural and urban areas has resulted into an increase in the number of affected individuals in the rural areas making the epidemic not only a problem of the people in the urban areas (Seeley et al 1993)

Legal support to people living with HIV/AIDS should also be considered in the HBC programs as the rights of the people living with HIV/AIDS are always violated leading them to lack right to properties particularly widowers, lack of right to privacy, confidentiality, access to acceptable healthcare, reproductive and sexual health services, employment, education, freedom of movement and the right to travel (FHI 2004)

## **2.5 HBC volunteers**

HBC volunteers are the main link between the HBC organization and the patients. Different factors around the volunteers also determine their level of providing services. The assumed factors in this study include education level, HBC training, age, sex, personal responsibilities and motivation attached.

According to Lindsey (2002) most of the care givers are family members who are usually women and young girls. The care of the sick falls to women who are also overburdened by other responsibilities. Home based care volunteers are the major source of help for the people dying of AIDS despite their limited trainings and they are the potential and viable asset that needs to be mobilised in order to do better in support of HBC programmes. According to Campbell (2005) HBC volunteers experience mental and physical stress, along with all these they are also committed to their normal routine task which keeps them living and some of them could be working outside their homes and their evening are filled with home chores. But there are positive issues working as a care giver; this include knowing their own strength in caring for the patients and learning to become patients advocate, gaining caring experiences including caring for themselves and their relatives.

Home based care volunteer's lack appropriate training and the lack of knowledge among home-based caregivers is identified to be one of the contributions towards poor quality of HBC care.

A study done in Blantyre, Malawi (Zimba & McInerney 2001), indicated that lack of prior preparation including training the home based care givers is a factor contributing to poor service. Akintola (2004) also found out that volunteers are mostly not motivated and in most cases they are paid small stipend for transport.

Another study has pointed out that as a motivation, it is important to give skills to volunteers so that they can confidently perform the caring work and this include giving some basic HIV/AIDS education, nursing and care orientation to the family home care givers (Sepulveda et al 2003).

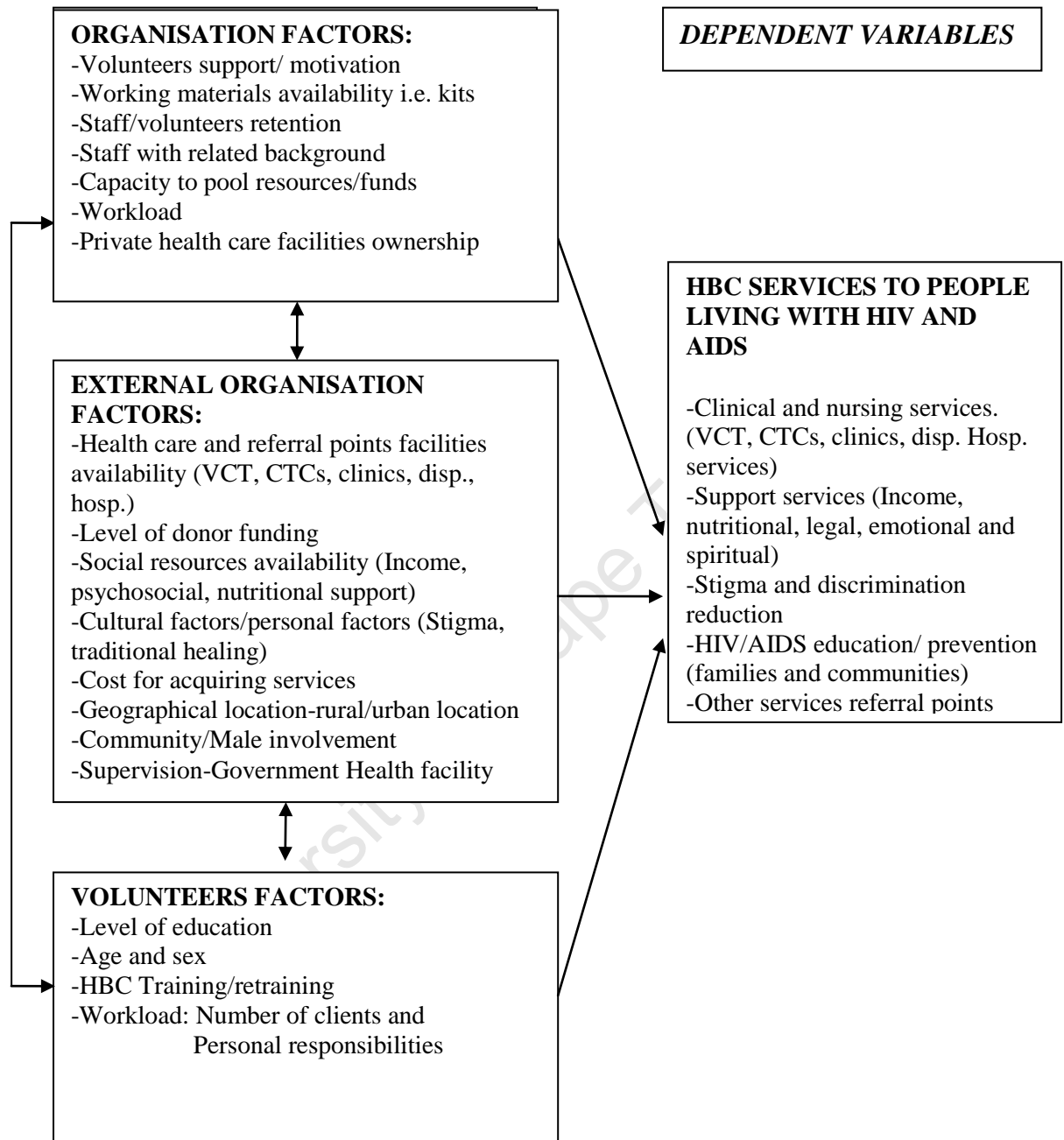
Transport is another important motivation and means of making volunteers work to be easy. An organisation motivating volunteers by providing bicycles to the HBC Volunteers in Namibia reported a huge impact on the volunteers' performance when they were supported with this means of transport (<http://www.benbikes.org.za/namibia>). This organization reported that 35% of the volunteers could serve more patients up to double the number they were serving before and they could spend 40% more time with the clients. The volunteer could also spend less time of travel and could carry more supplies during patient's visits.

According to Fisher and MCDaid (1996) home based care programmes should be keen on the selection of the volunteers, it is suggested that they should be matured, responsible and reliable people who are able to undertake tasks with the minimum of supervision, either their continual support and motivation was also further emphasised.

## **2.6. The conceptual framework**

The literature has led to a conceptual frame work that guides the study in exploring the factors that influence the home based care services provision. The literature lead this study to presume that there are factors influencing or hindering HBC services at each level of key HBC stakeholders mentioned. These hindering factors also make it difficult to keep the principles of home based care. The conceptual framework is constructed by relating the principles for successful HBC services, factors that influence provision of home based care service pointed out by the literature and the three levels of home based care stakeholders.

Figure 2: A simple model of factors influencing the provision of home based care services.



In the model above it has been assumed that the factors influencing the provision of HBC services can be grouped into three categories; internal organization factors, external organization factors and HBC volunteer factors. These presumed factors from each category form the group of independent variables which are the factors assumed to influence services provision. The HBC services that are supposed to come out of the HBC programs as the result of the interaction of the above factors are considered as the dependent variables.

## **2.7 Conclusion**

The literature review shed some light on the services that are supposed to be provided by the HBC programs and also indicated some factors that hinder the provision of these services. The common factors emerging include unequal distribution of HBC services between rural and urban/ semi urban areas, poor infrastructures including roads. Other factors are the lack or poor access to referral points for different required services including VCT, dispensaries and hospitals, lack of support services such as income and nutritional support. The literature indicated the importance of community volunteers in HBC programs but further pointed out that they are lacking motivation and training. Lack of funds and human resource among the HBC organization was also reported to be influencing the HBC services. The factors indicated by the literature are the factors that hinder access to health care service likewise home based care services, the issues of physical access due to poor roads, personal hindrances such as stigma and the difficulties to afford the services due to financial constraints and the availability of the services.

## Chapter three

### Methodology

*The chapter discusses the study design, the sample subject selection, implementation procedures and data collection and the methods used to manage the data.*

#### 3.1 Study design

The study used primary quantitative data in studying the determinants of home based care services provision in the Tanzanian context.

A quantitative method was preferred since it is reliable and it allows the collection of supplementary information especially with the open ended questions. Primary data collection allows pre testing of the questionnaires prior to actual data collection of which increases reliability. Primary data collection permits some flexibility as it allows restructuring of the questions incase the interviewee is not well grasping the questions (Paiva 1992).

According to David (1993) face to face interviews enables interviewers to build good relationship, trust and support with respondents, this makes it easy to collect information which could have not been revealed using another method of data collection.

The disadvantage of this method is that it is difficult to standardize the interview situation to ensure that the interviewer does not influence the respondents' answers.

It is also presumed that the best information for this particular study could be the one coming direct from the grass roots, in this case those who are actually implementing the HBC activities. The study collected information at two levels; the first level is the heads of the organizations carrying out the HBC activities under "Hope" programme and the second level is the volunteers providing the HBC service from the sampled organizations.

### **3.2 Study population, Sample size and Sampling method**

#### **Study population**

The population under the study is the organizations carrying out “Hope” home based care programme in Tanzania working in the rural and peri urban areas. The researcher don't have a relationship with “Hope” program and the study chose this program because it was the biggest home based care program in the country.

A simple purposive sample of 8 NGOs out of 23 carrying out HBC programmes under “Hope” were selected the reason being to get a good representation of NGOs from different location such as from the rural and peri urban settings. The initial plan was to interview 10 NGOs but it was later found out that some of the sampled organizations were dropped by the donor and hence the study ended up with a sample of 8 NGOs. The sample size of 8 organizations and 120 volunteers was purposively set due to time and resources constraints.

#### **Sample size and Sampling method**

A systematic sampling was done to select the Volunteers while the organizations were purposively selected in order to get representation of the regions carrying out the program in the rural and peri urban locations. A sampling unit at the first level is an organisation and at the second level is a volunteer providing the HBC services.

In selecting the volunteer to be interviewed a systematic sampling method was used, according to Katzenellenbogen et al (1997) in using systematic sampling an individual can be selected after  $i^{\text{th}}$  interval in the list. This interval is determined by the sample intended in the list; if the selected organisation has  $N$  total number of individuals and a sampled of  $n$  individuals is intended, then the sampling interval is  $N/n=i$ , then an individual is selected after every  $i^{\text{th}}$  individual in the list.

The list of Volunteers from each selected organization was obtained (Table 1 below) and the total number of volunteers was calculated which is 495( $N$ ), an intended sample of 120( $n$ ) volunteers was used to calculate  $i$  (4) which was used to calculate the proportional of the number of volunteers from each organization and the interval to be used to select an individual volunteer. The interval was applied to each organization and a sample of 120 volunteer was obtained.

**Table 1. Volunteers sampling**

<b>Organizations codes</b>	<b>Total Volunteers</b>	<b>Number of volunteers sampled</b>
01	24	6
02	32	8
03	36	9
04	50	12
05	54	13
06	70	17
07	128	31
08	101	24
<b>N</b>	<b>495</b>	<b>Total 120</b>
<b>N</b>	<b>120</b>	
<b>I</b>	<b>4</b>	

### **3.3 Ethical consideration**

The consent to participate in this study was sought, the interviewees were assured of the anonymity of the information to be provided, that the information to be collected is for the purpose of this study only and not otherwise, it was also explained to them that they are free to drop from the study if they wish to do so. The consent forms were filled and signed by all the interviewees who agreed to participate. The information collected is safely kept and can not be disseminated without any prior agreement with the stakeholders who include the interviewees (Annex C: Consent form)

### **3.4 Implementation**

#### **Fieldwork preparation**

The heads of the organisations were informed by telephone and later official letters were sent to them stipulating the aim of the study and the possible dates for the visits.

The lists of the volunteers were available at the programme level and the sampled volunteers were communicated to the heads of the organisations so that they can inform them on the possible interview dates.

Interviews with the organisations leaders were conducted in their respective offices while volunteers were interviewed in their locations.

## **Data collection**

Primary quantitative data was collected using structured questionnaires through direct interviews. (Appendix A: Volunteers questionnaire, Appendix B: NGO leader's questionnaire). At the organisations level the leaders who could provide information in regard to the HBC programme activities being undertaken were interviewed; at the volunteers level sampled volunteers from each organization were interviewed.

Two questionnaires; one for the organization leader and a second one for the volunteers were structured to collect the information on possible factors that influence home based care services provision. These factors are grouped into internal and external organizational factors and other factors that relates with the volunteers.

## **3.5 Validity and Reliability**

Both questionnaires were pre tested so as to insure that the questions are well understood. Relevant issues observed from the pre test were incorporated in the final questionnaires.

Questionnaires were comprised of closed and open ended questions and respondents were given enough time to give out their answers, they were also encouraged to ask for clarifications whenever the questions were not well understood. Open ended questions enabled more elaborate answers and to get individuals best ideas. For reliability the study also ensured that the same questionnaires were used for data collection throughout the study.

The shortcoming in the data collections include the respondents missing to follow up; these were few volunteer who were not available during the interview exercise the reasons being that some of them were out on their own business and to the farming areas.

These few missed respondents were replaced by volunteers of the same characteristics from the same area, though this could have lead to non response bias. A minimum recall bias is also expected as some of the respondents could have failed to well remember some of the issues interviewed. The possibilities of interviewer and respondents bias are common in interviews an example is where respondents give imaginary answers just to impress the interviewer (Kothari 1990).

Although the volunteer were assured of the anonymity of the information to be provided but there is a slight chance that some of them could have been worried to give out the fair answers just in fear of tarnishing the names of their organizations.

This is from the fact that volunteers knew that their leaders were aware they have been selected to participate in the study. The volunteers could have also reported wrong information particularly for the issues of their interest hoping that the study may forward their concerns for support or motivation. Other studies Barath & Cannell (1976) and Benson (1946) have indicated that researcher induced bias can not be avoided in some studies, interviews voice and manner can some how bias the answers from the respondents.

### **3.6 Study limitation and scope**

The study limitations include sample size which was fairly small due to resources limitation such as time and funds, larger sample could have provided more precise results. The government model of providing HBC services was also not incorporated in this study, it could have been important to compare the factors that hinder HBC services between the government and private model of HBC services provision. Collecting information from one program could have affected the results of the study since it does not provide a wide range of responses and the respondents may give answers that defend their program resulting to respondents' bias.

The assumptions under data collection are; the respondents will provide true information and will not provide responses which are in their favour. The second assumption is that the respondents are self motivated to respond to the interview.

### **3.7 Data management**

#### **Data processing**

Data management programs that were used in processing the data were Epidata, stata transfer and STATA programs. Questionnaires from the field were manually edited and coded and answers from the open ended questions were grouped or classified accordingly. The data entry screen, data entry, consistency checks and data cleaning were done using Epidata program. Stata transfer program was used to transfer the cleaned data to Stata program for analysis.

## **Data analysis**

### **Descriptive statistics**

To get the relevant results from the data different variables under the study were tabulated and the percentages and frequencies of different responses provided were summarized in tables.

## Chapter four

### Results

*The chapter shows the results coming from the study. It presents the internal and external organization factors and volunteers' factors that influence HBC services provision. The association between variables in question is also presented.*

#### 4.0 Introduction

The data collection exercise went for the period of two months were eight leaders from the selected organizations were interviewed. Due to missing to follow up the study ended up interviewing 113 Volunteers from the sampled 8 organizations implementing “Hope” HBC in four regions of Tanzania were interviewed.

Direct interviews using structured questionnaires were administered to the respondents and all relevant answers were filled in the intended questionnaires with the assistance of two field assistants who were oriented on the data collection tools and other field work procedures and norms.

The two questionnaires were structured to examine the internal and external organization factors and the volunteer factors that were presumed to be influencing HBC services provision. The association between factors was also explored. The assumed internal organization factors included staff retention, HBC kits availability and support and motivation to volunteers. Other related factors examined were the organization HBC experience, existence of staff with medical background and program monitoring.

The presumed external organization factors included access to referral points, availability of support in terms of food, legal, spiritual and income support. Other external factors studied were the availability and geographical access to referral points, field support from the supervisors, cultural factors and existence of stigma. Also the study looked at community support and male involvement in HBC activities.

The volunteers' factors studied are the ones that relate with the HBC volunteers themselves. The factors include their level of education, personal responsibilities, volunteers' workload and motivation. The volunteers were also assessed on the level of referrals provision to other HBC related services particularly VCT.

Other issue that was examined at the volunteers' level was their level of services provision looking at referrals to VCT.

### **Organisations characteristics**

Table 2 below summaries the characteristics of the 8 organizations interviewed, 2 of them are FBOs and 5 are NGOs and 1 is a CBO. For the working locations, 3 organisations are working in the rural areas while 5 are working in peri urban. It was also noted that only 2 organisations own health care facilities and of the two who own the facilities one own a hospital while the other own a clinic and dispensary.

**Table 2. Organizations summary of figures**

<b>Organisation codes</b>	<b>Category</b>	<b>Working Location</b>	<b>Male patients</b>	<b>Female patients</b>	<b>Total OVC</b>
01	NGO	Peri urban	192	232	808
02	FBO	Rural	203	256	1,157
03	NGO	Peri urban	241	287	1,333
04	NGO	Peri urban	254	363	1,451
05	NGO	Peri urban	263	407	2,303
06	NGO	Peri urban	290	434	3,141
07	CBO	Rural	424	495	3,299
08	FBO	Rural	685	1,001	4,683
<b>Total</b>			<b>2,552</b>	<b>3,475</b>	<b>18,175</b>

## **4.1 Internal Organization Factors**

### **4.1.1 Organizations HBC experience**

Most of the organizations interviewed have the HBC working experience in terms of the number of working years where the lowest two organisations had an experience of 2 years while the highest two organizations had an experience of 8 years. Either all NGOs were found to be having at least one staff with medical background and mostly a nurse assistant.

#### 4.1.2 Staff retention

Most of these NGOs have shown a tendency of staff drop out of between 1 to 3 staffs while some NGOs have volunteers drop out of up to 8 during the period of program implementation.

#### 4.1.3 Drugs supply-HBC kits

Table 3 below indicates that 97% of the volunteers interviewed reported that they do not have full equipped HBC kits in most of the time, the kits are occasionally refilled and even when replenished some of the basic items goes missing. The heads of the organization gave their views on the same matter and it was only one organization leader who agreed that the volunteers always have equipped HBC kits. This concludes that the availability of HBC kits for the volunteers is inadequate and irregular.

**Table 3. If HBC Volunteers have equipped HBC kits and if receive supportive Supervision from supervisors (n=113)**

Responses /Attributes	HBC kits availability		Supervisors support
	Volunteers	NGOs leaders	Volunteers
Yes	3(3%)	1	57(50%)
No	110 (97%)	7	56(50%)
Total	113(100%)	8	113(100%)

#### Support and motivation to volunteers

Organization leaders gave their general assessment of their volunteers working morale where 3 organisations reported that their volunteers have high working morale, 3 said it is average and 2 low (Table 4). Combing the organizations which said average and low morale translates that the volunteers have low motivation or average motivation.

**Table 4 Volunteers working morale (8 Organizations)**

<u>Working morale</u>	<u>Freq.</u>	<u>Percent</u>	<u>cum</u>
High	3	37.50	37.50
Average	3	37.50	75.00
Low	2	25.50	100.00

In finding out more about the support, the volunteers were interviewed on whether they always get their monthly allowance on time and 53% of the volunteers responded that they do not get it on time and added that it is too little.

Also 35% of the volunteers disclosed that in case there will emerge another HBC organization providing better allowances than were they are now they will be ready to shift. Support to volunteers in terms of transport is also inadequate, as indicated in table 5, about 13% of the volunteers reported to be walking long distances to visit their patients the reason is that the bicycles provided are worn out.

**Table 5 Volunteers means of transport to far distance patients (n=113)**

<b>Means of transport</b>	<b>Freq.</b>	<b>Percent</b>
Bicycle	97	85.84
On foot	15	13.27
Other	1	0.88

Motivation in terms of giving feedback was also looked at and all 8 organizations agreed to be giving some feed back to their volunteers particularly on the program progress and sharing other relevant program proceedings.

Also 98% of the volunteers agreed to be given time to give out their views during the meetings though some of them remarked that few or little of their problems get solved.

Most of these organisations depend on the little allowance allocate from the donor fund for motivating the volunteers. It was found out that only 1 organization has other means of motivating their volunteer and this is by involving them in other activities for a pay.

### **Program monitoring**

It is important for the programs to collect data for monitoring and evaluation since it is an important aspect in the programs implementation as it gives the direction of the program such as the progress on the implementation of the projects' targeted activities.

The study found out from the volunteers that they are collecting all the required data for monitoring and evaluation with 97% of the volunteers responding that they do collect all the data as required. Few volunteers 10% added that the forms they use for data collection are many of which increases workload.

## 4.2 External Organization factors

The factors presented include those assessed from the organization leaders and the volunteers. These are factors that can not be controlled by the organization providing HBC services but they play a major role in shaping the nature of HBC services being provided.

### 4.2.1 Availability and access to HBC referral points.

#### VCT, CTC and other health care facilities

All volunteers interviewed in this study reported that there are referral points for VCT, CTC and health facilities, but added that in some catchment areas they are located very far and therefore access to these services is a big challenge. Either some of the NGOs reported poor infrastructure as one of the factors hindering PLHIV from accessing these health care facilities, these are the remote and mountainous areas where there are no clear demarcated roads.

The study hypothesized that patients in the urban areas have higher access to HBC related services than in the rural areas. In this hypothesis we compared the levels of referrals to VCT between rural and peri urban. In finding out the levels of referrals for VCT and CTC services the study found out that only 22% in the rural could refer while in the peri urban 75% could refer. At least 23% of the volunteers could refer all of their patients to CTC as indicated in table 6.1 and 6.2 below.

**Table 6.1 If volunteers could refer all of their patients to VCT for the qualifying patients (n=113)**

(Working location)	(If could refer all patients for services, VCT)		Total
	Yes	No	
Rural	16 22%	57 78%	73 100.00
Peri-urban	30 75%	10 25%	40 100.00

**Table 6.2 If volunteers could refer all of their patients to CTC for the qualifying patients (n=113)**

(Working location)	(If could refer all patients for services, CTC)		Total
	Yes	No	
Rural	0 0.00	73 100%	73 100.00
Peri-urban	9 23%	31 77%	40 100.00

In finding out if the referral points are accessible, the study looked at the access to VCT and CTC were the volunteers were asked on whether there is any cost involved in reaching these facilities. Table 7 below shows that 57% and 88% agreed that there is a transport cost getting to VCT and CTCs respectively. The same number indicated that most of the VCT and CTCs are located in the townships and urban areas.

Also the volunteers were interviewed on geographical location of the facilities where they can refer their clients for other HBC related services and 52% of the volunteers gave their opinion that the facilities are far from where they live.

**Table 7 Referral points' availability and access in terms of transport cost (n=113)**

Info.	VCT		Transport Cost to get to VCT		CTC		Transport Cost to get to CTC	
	Available	Not available	Yes	No	Available	Not available	Yes	No
<b>Total response</b>	113	0	64	49	113	0	100	13
<b>% of the total</b>	100%	0%	57%	43%	100%	0%	88%	12%

### Income support

Referral points for income and nutrition support were reported by all the volunteers to be totally not available in the program area as the results are depicted in table 8 below.

The programs under hope are supporting the patients families with income generating activities though to a very minimum level and all eight organisations remarked that the level of funding on income generating activities is very low as in comparison to the needs.

Either when these organizations were asked to give their general assessment on income in the PLHIV families, all 8 organisations responded that the families have very poor income.

**Table 8 Availability of other referral points (n=113)**

Info.	Nutrition support		IGAs support		Legal support		Emotional support		OI treatment		Spiritual support	
	Available	Not available	Available	Not available	Available	Not available	Available	Not available	Available	Not available	Available	Not available
<b>Responses</b>												
<b>Total responses</b>	0	113	0	113	111	2	92	21	113	0	112	1
<b>% of the total</b>	100	0	43	100	98	2	81	19	100	0	99	1

### Nutrition support

The study found out that nutrition support is being provided to a very minimum level since all the 8 organisations reported that inadequate food support is one of the major challenges facing their programs. Either all volunteer responded that there is no referral point for nutritional support in their working areas as indicated in table 8 above.

The NGOs leaders were asked to give their experience and the general assessment on the food availability in the families they are serving and 7(87%) out of 8 organisations answered that the food situation in the families they are serving is very poor.

### **Emotional support**

Emotional support to the patients and their respective families encompasses counselling, spiritual care through volunteers, peer groups support and pastoral support.

Spiritual support was highly pronounced to be well provided to the clients and all volunteers reported the existence of referral points for emotional support which include churches, mosques and peer groups.

Of the 8 organisations surveyed 3 organisations responded that they have peer groups support while 5 said that the peer groups exists but not in all areas.

### **Legal support**

All volunteers reported the existence of legal support point where referrals at the lower levels starts at the village leadership and then to primary courts at the district level.

When volunteers interviewed if they could refer patients who needed legal services 61% responded that they did not have any issue that needed legal service, 42% could do so while 2% could not.

#### **4.2.2 Availability of Prevention programs**

It was reported by both parties interviewed that most of the prevention programs such as those advocating condoms use, behaviour change and HIV education were reported to be existing but it was further added that the programs are mostly carried out in the urban areas and in the townships in peri urban areas therefore the prevention program are not reaching the deep remote areas.

#### **4.2.3. Level of donor funding**

Adequate and consistent funding contributes greatly to a successful HBC program, the level of funding is another issue studied in finding out if the funding is adequate and hence giving the picture of organizations work load and sustainability. From table 9 below none of the organizations agreed that the funds are satisfactory while 5 (62%) organizations said that the funding is average and the remaining 3(38%) said that its not satisfactory as in comparison to the number of clients in need of the services.

**Table 9 Level of program funding (n=8 NGO Leaders)**

Funding levels	Freq.	Percent
Average	5	62.50%
Not satisfactory	3	37.50%

The programs are lacking donors and internal support such as from the government and other stakeholders. The support to supplement the program budget from the current donor is very meagre or none existence and only 5 (62%) programs agreed to be getting little funds from other donors especially for OVC activities.

#### **4.2.4 Cultural factors**

The study also tried to find out if there are any cultural factors that hinder the provision of HBC services. There are some cultural factors and believes that hinder HBC activities as revealed by the volunteers interviewed, 34 (30%) of them reported that superstitious believes and relying on traditional medicine is one of the factors hindering HBC services provision in some of the program areas. Some of the volunteers disclosed that their patients take traditional medicine along with other medicine including ARVs, or some start trying the traditional medicine and later turn into western medicine and vice versa and this leads to patients getting enrolled into HBC program when their health conditions are worse.

Either one organization leader reported that though religion has played a bid role in shaping the HBC services especially with the spiritual services and counselling and other support through small Christian communities but there are emerging few cases were it is becoming a hindrance since some of the Christians so called “born again” have stopped taking ARVs claiming that Jesus has served them.

#### **4.2.5 Supportive supervision to volunteers**

The study looked at support to volunteer in terms of supportive supervision since this is also one of the key aspects for one to perform. The HBC activities carried out by these organizations is set in search a way that the volunteers are supposed to receive regular supervision from government health facility HBC supervisor or focal person.

The study found out that supervision provided to volunteer is inadequate as indicated by table 3 section 4.1.3 above, 50% of the volunteers reported to be lacking supportive supervision. In some area the volunteers reported that the supervisors are not in place.

#### 4.2.6 Community support and male involvement

When the volunteers were interviewed on whether men are involved in the care of the patients in their homes (table 10) 65% reported that men do so also 60% of the volunteers suggested that the community should be involved in supporting home based care activities in their areas this shows that there is a low community support in caring for their patients.

**Table 10. Community and Male involvement (n=113)**

<b>Responses</b>	<b>If community participate</b>	<b>If men participate</b>
Yes	56(50%)	65(57%)
No & Not always	57(50%)	48(43%)
Total	113(100%)	113(100%)

Table 11 below gives the results on whether family member support their patients in following up drugs intake time tables. 74% of the volunteers responded that family members do so, 21% responded that some few families do while 4% reported families do not support.

**Table 11. If family members assist their patients to follow up drugs intake (n=113)**

<b><u>If assist with drugs adherence</u></b>	<b><u>Freq.</u></b>	<b><u>Percent</u></b>
Yes	84	74.34
No	4	3.54
Not all (Some)	24	21.24
None on ARVs	1	0.88

#### **4.2.7 Stigma and discrimination**

The study shows that stigma still exists in the communities with 92% of the volunteers saying that the reason for some of their patients to have not attended VCT could be attributed to stigma.

When the volunteers were asked on what is in the community that is hindering the provision of HBC services, 28 (25%) of 113 volunteers interviewed responded strongly that stigma is still a big issue in the community and in the families that they are serving adding that with all the HIV education provided to the families a number of their patients still do not want to test for HIV.

#### **4.3 HBC Volunteer factors**

The study presumed that there are factors associated with volunteers that influence the level of HBC services provision. In this study the assumed factors are age, sex, education level, acceptable HBC training and personal responsibilities attached to volunteers.

##### **4.3.1 Age, sex and marital status**

It was important to examine the age, sex and marital status of the total volunteers in these organizations since these factors could be having some influence in providing HBC services provision.

The sex distribution of the volunteers from the eight organizations surveyed was 43% and 57% for male and female volunteers respectively.. Another study also found out that male participation in the care for patients is much more inclined to women (Akintola 2004).

The study found out that the volunteer's age to be between 20 and 50 and with the majority of them been between 30 and 40 years of age, 3% were above 50 years of age.

##### **4.3.2 Volunteer's education level**

Most of the volunteers were found to be having primary education (70%) and 29% had secondary education, only 1% had higher education making a total of only 30% for post primary education.

**Table 12. Interviewed Volunteers' characteristics**

Info.	Vol. sex		Educ. Level		Marital status		Occupation			
Category	Male	Female	Primary	Post_primary	Marriage	Others	None	Agricultural farming	Small business	Employed
<b>Sub total</b>	54	59	79	34	82	31	27	59	14	13
<b>% of the total</b>	48%	52%	70%	30%	73%	27%	24%	52%	12%	12%

#### 4.3.3 HBC Training to volunteers

All volunteers reported to have undergone one month HBC training which followed the MOH HBC curriculum but again 49 (43%) volunteers out 113 commented that they need HBC refresher course in order to match with the new issues coming out in HBC particularly on emotional counselling and palliative care. Some were complaining that they are getting lots of questions from the patients on ARVs and since they have a very limited HBC knowledge they can't help much in that area.

Volunteers were tested on their basic HBC knowledge where they were asked to give out the specific method of establishing whether one is HIV positive. Table 13 below give their respective responses. 97% could mention blood test while 3% did not; either 38% mentioned through symptoms as another method of establishing whether one is HIV positive.

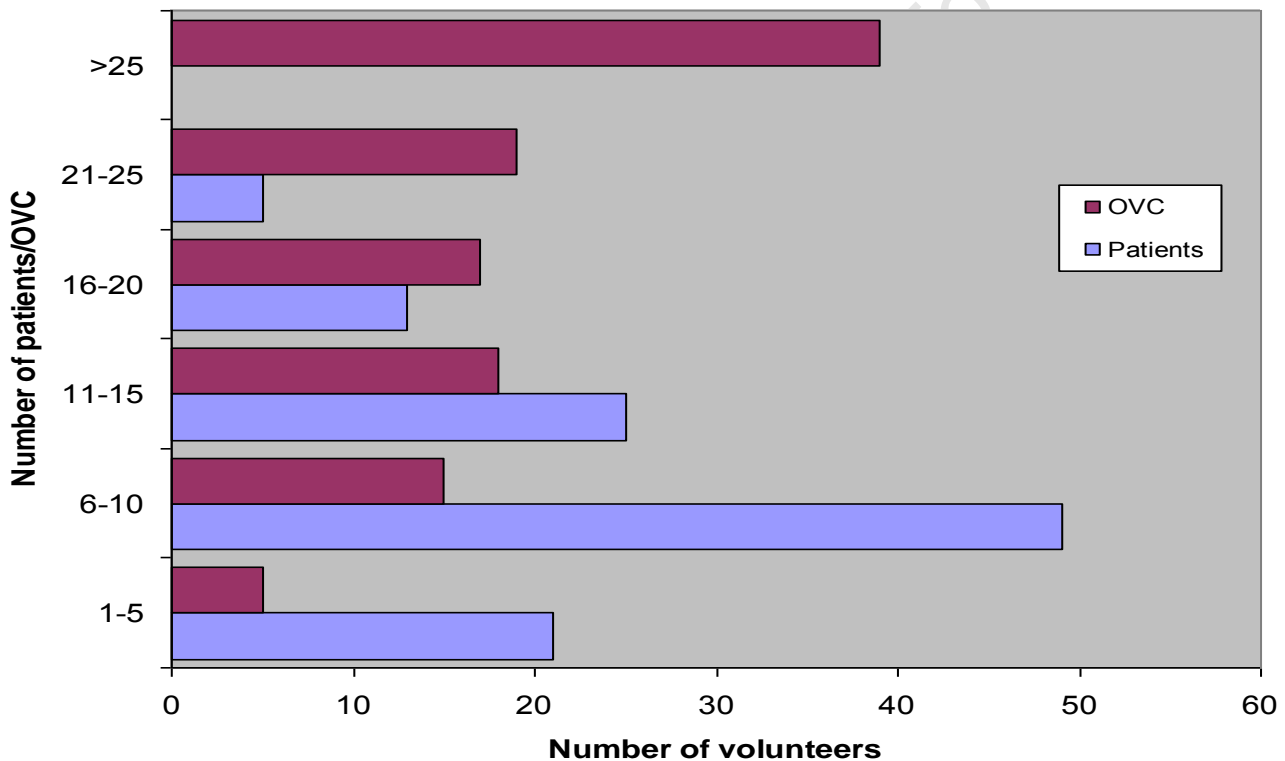
**Table 13 Volunteers' basic HBC knowledge (n=113)**

Responses	Through Blood test		Through symptoms	
Mentioned	110	97%	43	38%
Not mentioned	3	3%	70	62%
Total	113	100%	113	100%

#### 4.3.4 Volunteer workload

The study looked at volunteer's workload by analysing the number of clients being served by the volunteers. The program recommends an average of 15 patients and 25 OVC per volunteer but as indicated in chart 1 below the study found out that the average number of clients being served by volunteers varies from one organization to another. The study shows that more than 38% of the volunteers are serving more than 15 patients and 34% of the volunteers are serving more than 25 OVC. Either 5 volunteers were found to be serving about 21 to 25 patients.

Chart 1 Patients and OVC per Volunteer



Furthermore in studying volunteers' workload the study examined the nature of other activities attached to the volunteers. This has a great influence on the volunteers performance as the more the volunteers are committed to their other activities the less the attention they would give to the HBC activities. Volunteers were found to be having their normal routine occupations which earns them living.

As indicated in table 12 section 4.3.2 above some volunteers were either doing agricultural farming (52%), small businesses and employed (12%) each and no formal activity (24%). Along with their normal activities the majority of the volunteers were found to be having other responsibilities out of their main activities which include care for the children for the women and gardening and animal keeping for both men and women.

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## Chapter five

### Discussion

*The chapter discusses the results presented in relation to the research objectives and other related literature*

#### **5.1 Introduction**

The results coming from the study indicate that there are different factors that determine HBC services provision. These factors are grouped into internal and external organization factors and volunteers' factors. The study found out that availability of referral points for services that compliments HBC services such as VCT, CTC and other health facilities varies from rural to peri urban settings.

The influencing factors that are within the organizations providing HBC services are inadequate supply of HBC kits, lack of support and motivation to volunteers, incomplete program monitoring, lack of refresher trainings to volunteers and the organization inability to solicit funds to meet all the required services and for the program sustainability. The influencing factors that are situated outside the organizations are unavailability of referral points and their access, inadequate support services, unavailability of HIV preventions programs, lack of community and male involvement, existence of stigma and discrimination, lack of support and supervision from government health facility supervisors, existence of cultural factors and the low level of donor funding. Volunteers factors found are; education level, lack of HBC refresher training and workload resulting from the higher number of clients and personal responsibilities attached to volunteers.

#### **5.2 Factors associated with HBC organisations.**

##### **5.2.1 Organisations characteristics**

##### **HBC organizations health facility ownership**

The study found out that only two organisations own a health care facility of which one own a hospital while the second is running a clinic and dispensary. The facilities owned by these organizations provide HBC related health care services including VCT of which could be strength towards HBC services provision.

It was revealed by one organisation which claimed to be having HBC kits through out the time as they have an advantage of borrowing drugs from their facility when the program is out of HBC kits supplies. Further studies to find out if organisations with health care facilities have advantage in providing HBC services than those with no facilities is of great paramount.

### **PLHIV sex distribution**

Another demographic data of interest coming from the study is the sex distribution of the patients were female patients are more than male. This could be attributed to the associated stigma resulting to male hiding from HBC services just in fear of being recognized as being sick. The sex distribution of the patients was expected to be somehow the same since other studies indicates that nearly half of the HIV infected individuals are women (<http://www.unifem-eseasia.org>). According to Vicci (2002), gender inequality has made women more susceptible to the disease since they are less deprived in many ways including less information on HIV/AIDS prevention and fewer resources to take preventative measures. For this reason Tanzania has to increase the efforts to challenge gender stereotypes and inequality.

### **5.2.2 Organisations HBC experience**

A formalized home based care for the people living with HIV/AIDS is a new area in the country which has emerged as the result of impacts of HIV/AIDS. Although most of the organizations studied have some HBC working experience in terms of the number of working years the experience should not be considered as a major advantage towards providing the services since the HBC which was being carried out in the past was more of traditional HBC with much more concentration on home visit without any major care and treatment support. The past HBC model was not been monitored under standard HBC guideline and training curriculums where the issue of providing comprehensive care to PLHIV through referrals is key.

### **5.2.3 Availability of HBC kits and supplies**

The study found out that most of the volunteers do not have equipped HBC kits in most of the time, it is on and off and even when replenished some of the basic items goes missing.

For the volunteers to be able to undertake minor nursing and clinical care at their level they need to have HBC essential supplies including HBC kits. The heads of the organization gave their views on the same matter and it was only one organization leader who agreed that the volunteers always have HBC kits and this could have been due to the fact that this organization own a hospital and their HBC program is allowed to borrow drugs from this hospital when the volunteers kits are out of stock. This concludes that the availability of HBC kits for the volunteers is inadequate and irregular.

One of the HIV/AIDS care and treatment goals under clinical care is to provide essential drugs for the treatment of opportunistic infections and ARV (WHO 2004a). Therefore the availability of health care facilities in the HBC program areas is important since it would facilitate the provision of clinical and nursing care services which include the treatment of opportunistic infection. All volunteers interviewed in the study reported that there are VCTs and health care facilities including clinics and dispensaries although it was added that the issues of access to these services is another question ahead as in some areas these services are situated far from patients proximities.

People living with HIV/AIDS need clinical and nursing care in order to reduce the morbidity and mortality associated with the diseases. These services include the diagnosis and treatment of opportunistic infections (OI) and HIV/AIDS related illnesses and the provision and the management of ARVs. Palliative therapies and alternative remedies should also be considered in HBC programs. Unavailability of VCT services is a hindrance factor since counseling and testing is an entry point into HIV/AIDS care and treatment services including HBC services. VCT services has also proved to be an area in promoting safer sexual behaviors and hence reducing HIV transmission and enabling affected individual to disclose their HIV status. VCT center has also played a major role in reducing stigma associated with the disease (<http://www.fhi.org/en/HIVAIDS/pub/fact/carsupp.htm>)

#### **5.2.4 Staff and volunteer support and motivation**

The study found out that there is a tendency of staff drop out and volunteer withdraw. Some of the NGOs reported to have lost some of their volunteers from death since they are making the use of some of the HIV patients as their community home based care volunteers as they make a good example in community sensitisation.

It was further studied that these organizations do not have any other means of motivating their volunteers rather than the little monthly allowance allocated from the donor fund. The volunteers reported that the allowance given is too little and do not reach them on time. This indicates that there is low motivation resulting from unmet expectations of which can make volunteers lose their working morale. It is important to retain staff since they are the organizations resource as they contribute to the success of organization mission. Regular drop out of staff who the organization has invested in building their capacity means poor performance of the organization.

The study found out that there is inadequate support and supervision as half of the volunteers reported to be lacking supervision. The study found out that in some areas the volunteers were not only lacking supervisors but also the supervisors are not in place. The aspect of volunteers support and motivation in terms of availability of working materials and supplies is very crucial for the volunteers to provide good care. They should be supported with transport for visits and HBC kits. The volunteer's motivation and performance can be enhanced through supportive supervision and regular feedback on the performance and other program proceedings. The work of caring for the chronic patients causes physical and emotional challenges to the volunteers and the care givers in the homes.

Home based care programs should plan for various means of motivating volunteers for example through trainings, incentives, field work support and supervision, social activities and forums where they can air out their concerns. Winberg (2004) indicated that the quality of care to chronically ill patients can be improved by close field supervision and volunteers support. This goes along with the volunteer's emotional support in order to reduce stress which may be caused by the workload and witnessing lots of suffering of which they could not provide any major help. Volunteers just like the patients they are serving also need some form of psychosocial support as they are sharing lots of experiences with the patients.

The volunteers reported that the hardest part of their work is the fear to contract diseases. The results relates to those of Marincovitz et al (2004) where it was reported that the work of the volunteers goes further where they become the main care giver of the patients, the work which leads to stress related illness such as headache and backache and to make it worse they face the risk of infection such as TB and HIV.

All these issues alerts the HBC programs to critically come up with means of de-stressing the volunteers since the accumulation of stress would not only lower their performance but also may affect their physical and mental health.

Motivation in terms of giving feedback to the volunteers was also looked at and all eight organizations interviewed agreed to be giving some feed back reports on the program progress and sharing of other relevant program proceedings with their volunteers. The volunteers also agreed to be given time to air out their views during program meetings though with some remarks that few or little of their problems get solved. This is another area that needs a prompt attention because with the volunteers burn out the programs may experience a very high rate of volunteers drop out.

When the HBC volunteers were interviewed on what motivates them, most of them responded that it's from their desire to help patients and also they become very happy to see patients who were bedridden recovering and work again. They also added that among the patients they are serving include relatives and friends. The results from this study concurs with the findings from Marincowitz et al (2004) where it was reported that individual become volunteer because of the desire to help their own people and also they get some morale when they get appreciation from their patients and when they see their conditions improving. Volunteers were also found to be happy to provide knowledge and confidence around HIV/AIDS care to these families.

#### **5.2.5 Program monitoring**

It is important for the programs to collect the appropriate data for monitoring and evaluation since it is an important aspect in the programs implementation as it gives the direction of the program such as the progress on the implementation of the project targeted objectives and activities. The weakness learnt from the monitoring and evaluation process should be taken as a lesson for the improvement.

The study found out that the volunteers are collecting all the required data without any major difficulties. The next question is on whether these programs are making a good use of the data that is being collected such as for the program monitoring and evaluation.

Winberg (2004) reported that the quality of care to chronically ill patients can be improved by good data collection that can be used for monitoring program progress.

### **5.3 External organisations factors**

External HBC determinants are the factors outside the organisations but play a big role in shaping the provision of HBC services. The factors studied include networks or referral point's availability and access to other HBC services between urban and peri urban areas, level of donor funding and the workload, availability of prevention programs, cultural factors, stigma and discrimination. The study also looked at community support and male involvement in home based care activities. Other factors studied are the availability of support services such as income, emotional, nutritional and legal. Another factor presumed to be outside organizations is the availability of supervision from the government health facilities support to community volunteers.

#### **5.3.1 Rural and Peri urban access to HBC services.**

The study established that there is inadequate referrals point for HBC related services and in relation to this it was found that availability and access to HBC related services acquired from VCT, CTC and other health care facilities differs between geographical locations. This indicates that patients in the peri urban areas have higher access to services that compliment HBC services than those in the rural.

In finding out if the referral points are accessible; the study looked at the services to VCT and CTC in relation to volunteers who reported that there are costs involved for patients to get to VCT and CTC and to other health facilities. For this reason some patients would need fare for transport in order to get the services. Transport cost and impassable roads during rain seasons hinders volunteers from providing HBC services and for the patients to access health care services from VCT, CTCs and other health facilities. It was further reported that most of the VCT and CTC are located in the townships and urban areas.

In relation to this the study explored on the levels of referrals to VCT and CTC and in doing so the study established that most of the volunteers could not refer all of their patients to VCT and CTC. The results relates with those of (Ashnie et al 2006) which pointed out transport difficulties as one of the barriers to treatment for PLHIV.

The study found out that referrals are mostly done in the area of VCT, CTC and other health facilities for other related services including ARVs and medical treatment especially for opportunistic infections treatment. The volunteers from semi urban areas are found to be having higher chances of referring more patients to VCT services than those in the rural areas. This translates into unequal distribution of health care services since patients from rural areas go far distance to reach the health care related services, this call for a need to extend the services to reach more clients.

The modern HBC programs operates under the concept of continuum of care since the services for the people infected with HIV changes as they progress into illnesses and they need a range of services from home and to the health care facilities. Functioning referrals should be developed in order to meet the range of services required by the patients and their families. Organizations providing HBC services as single entities can not provide each and every service required. These services include clinical care, psychological support, socio economic support, involvement of community and their families and respect for human rights in terms of legal support (WHO 2004b; [www.fhi.org/en/HIVAIDS/pub/fact/carsupp.htm](http://www.fhi.org/en/HIVAIDS/pub/fact/carsupp.htm)).

Organization leaders also reported poor infrastructure in rural areas as one of the factors some clients to access HBC services, this is mostly in the remote and mountainous areas where there are no clear demarcated roads, this result concurs with Campbell (2005) were it was found that some of the patients were missing appointments in hospitals due to poor infrastructure in terms of poor roads.

This gives a picture that those patients in the peri urban areas have more access to HBC related services than those in the rural areas.

This is due to the fact that health care facilities are more situated in the urban/peri urban areas than in the rural areas.

This has a big impact in relation to the rural population composition of many African countries south of the Sub Sahara as it is indicated that the majority of the 150 million directly affected by the epidemic are more likely to be living in the rural areas. (<http://www.undp.org/hiv/publications/study/english/sp6ech1-2.htm>). Therefore there is a need to target rural areas in fight for the HIV because HIV prevalence rates are on increase in the rural areas. Ntozi (1997) put it clearly that most of the cost of HIV/AIDS is largely borne by rural communities because most of the HIV infected individuals in the urban areas moves back to their rural homes when the disease progress to the final stages. These places the rural households and particularly women, and health care systems into another burden that they cannot put aside. This escalates the rural poverty due to caring costs which include medical care, food and funeral expenses.

### **5.3.2 Access to other support services**

The study also looked at access to other support services such as income, nutritional, emotional and legal support services.

#### **Income and nutritional support**

The study shows that income and nutritional support is inadequate. Referral points for income and nutrition support were reported by all the volunteers to be totally not available in the program area.

The organizations studied report to be supporting the patients with food and income generating activities though to a very minimum level. All eight organisations remarked that the level of funding on income generating activities is very low as in comparison to the needs due to an increasingly number of clients.

Most of the Tanzanian population is living under one dollar a day, the rampant poverty situation among the community could be a clear reason to why the community can not contribute any feasible resource towards HBC programs. This has left the whole burden to the HBC organisations which have limited food budget or no budget at all ([www.oneworldyouthproject.org/mdg1.html](http://www.oneworldyouthproject.org/mdg1.html))

It was further added by all eight organisations that income and food support is one of the major challenge facing their programs and currently they are doing very little in this aspect.

When organizations leaders were asked to give their general assessment on income in the PLHIV families, the general assessment given by all eight organisations on income and food availability in the affected families is that the income levels are very low and there is no food security. The shortage of food is expected to be worse as Tanzania national estimate of food crop production reported a food shortage in 34% of the districts in 2005 and it was expected to rise up to 65% by January 2006 due to a prolonged drought conditions (REPOA 2006). Similar findings came from Tibaijuka (1997) that HIV/AIDS affected families are put into income and nutrition disputes which include isolation, loss of income, medical and transport expenses, funeral costs, and the unmet needs of orphaned children for education, shelter, nutrition, clothing, and other necessities. This is further accelerated with the fact that when parents die the income level of households drops hence low disposable income for buying food. A study by Ankra (1993) pointed out that there is lack of productive resources such as land for HIV/AIDS orphans as they lose their land as older members of the family do confiscate it and this leads to lowering their nutrition status.

Nutritional support is an important determinant of HBC services and according to WHO(2004c) people living with HIV/AIDSs and patients receiving medication for opportunistic infections or ARVs, their nutrition status can be influenced by the medication. It was added that it is the good nutrition that would take care of the impacts caused by the drugs of which will also enhance the immunity system. The provision of income generating activities in the families affected will pave way to a relief in these families, otherwise the medical trap of health care will still continue within these families hence worsening the conditions of the patients and the families affected (Ogotu 2005).

According to FHI (2007) house holds economic strengthening has dual impact since it enables these families to meet the cost of health care including transport to health facilities and make food available in their families.

It is also important to improve the level of education since it is key to development and in improving economic growth however in the case of African countries, the low gross domestic product (GDP) earned by these countries still make them find it difficult to invest in education (Kalipen et al 2004)

### **Emotional support**

Spiritual support was one of the services that were highly pronounced to be well provided to the clients as all volunteers reported the existence of referral points for emotional support through churches, mosques and PLHIV support groups. However from 8 organisations surveyed 3 organisations responded that they have PLHIV peer group support while 5 said that the peer groups exists but not in all areas.

Emotional support to the patients and their respective families is an important service since it enables people affected by HIV to cope with their fears and emotions. The communities, families and faith based entities should continue enhancing the existing networks especially in this era of HIV/AIDS were such networks are proving to be of great paramount in caring for the individuals affected and their families. One example of network of care for the sick people is the small Christian communities established in most parts of the country in Tanzania where Christian communities exist. Counselling aims at facilitating problems solving, understanding and increasing motivation at the times of crisis, to promote change and to assist individuals to accept information on health and adopt into its implications.

Spiritual and peer group support forms another kind of emotional support

(WHO 2000; <http://www.fhi.org/en/HIVAIDS/pub/fact/carsupp.htm>).

Therefore individuals providing counselling should strive to reach the minimum possible goals of counselling. Spiritual care and support through volunteers, therapy through peer groups or clubs for the people living with HIV/AIDs should also be promoted.

### **Legal support**

Legal support to people living with HIV/AIDs includes services that would promote equal access to care, reduction of all forms of discrimination, succession planning and protection of property (WHO 2004b).

The study found out that there is existence of legal support point where referrals at the lower levels starts at the village leadership and to the other levels of primary courts at the district level.

Although the volunteers reported that most of their patients did not need legal service but it was added that succession plan is a concern to the most adults who are terminally sick.

This raises a concern on whether the volunteers can handle other issues around legal support for the people living with HIV/AIDs.

Customary laws and remedial legislations have seized away widows who are also most likely to be infected with HIV their rights to inherit the wealth left by their partners. This include women rights to land and other properties such as animals after their husbands death (<http://www.undp.org/hiv/publications/study/english/sp6ech1-2.htm>)

The legal practitioners should go further and address the traditional practices which marginalise the people living with HIV/AIDS especially women.

### **5.3.3 Cultural factors**

Cultural factors especially witchcraft or superstitious believes and relying on traditional medicine featured as one of the factors hindering HBC services provision in some of the program areas. Volunteers reported that some patients accept HBC services when traditional healing fails, making them to join the services when their health conditions are worse. It was also reported that some patients take traditional medicine along with western medicine including ARVs. There is a need to conduct further studies to find out if by doing so it can result into any interaction or bad side effects. The results relates with the study from Mtombeni (2004) where patients and the families were found to be associating the disease with witchcraft and some patients were using traditional medicines right after coming back from the hospital However another study established that traditional healers play an important role in HIV/AIDS management where traditional healers were seen to be a resource for relief to PLHIV (Ashnie et al 2006).

Another finding of interest coming from the study in relation to believes is where religion was found to be a hindrance. The study found out that some PLHIV have stopped taking ARV claiming that they have being healed by god.

Similar results came from Ntozi (1997) that there were some churches called healing churches which claimed to be using the powers of Jesus to cure AIDS. This is also supported by Peltzer et al. (1989) that attention and prayers from traditional healers and churches provide psychological and emotional support to patients who are in the advanced stages of the disease. However this could be a hindrance towards the provision of care and treatment services to PLHIV as it may lead to patients developing resistance to drugs particularly when they stop taking the drugs.

#### **5.3.4 Stigma and discrimination**

The study indicates that there is stigma in the community and in the patient families since it was reported that one of the reasons for the patients not attending to VCT is associated with stigma. Stigma leads to failure to disclose HIV status and also shying away from attending to different related HBC services such as VCT and access to ARVs. Those who do not test also end up infecting others unknowingly. The study shows that stigma still exists in the communities with 92% of the volunteers reporting stigma and discrimination as the reason for some of their patients not attending to VCT services and this has been observed in the community and in the families that they are serving. It was further added that even some of the patients who attended to VCT and taking ARVs are doing it secretly without disclosing it to their partners. Stigma and discrimination has been mentioned by the volunteers and the heads of the organisations as one of the major challenges facing their day to day HBC activities. The results relate with those of McGrath et al (1993) who found out that AIDS patients did not want to inform their parents because they did not want to worry them. Incidents of rejection, especially by the neighbours, community isolation in the buses community and public were also reported by the same study.

Agyeman (1993) found that 16 out of 18 male patients did not inform their parents for fear of being blamed and excluded, either none of them told their children. But this is done at the expense of these individuals losing or missing different HIV/AIDS care services. Stigma and discrimination claims patients' rights to access health care services hence worsening the HIV/AIDS situation.

Stigma in the communities has not only hindered affected individuals from accessing health care services but also in other social services as it was remarked by Kamali et al (1996) that children are more likely to drop out of school due to financial difficulties, illness, and social stigma associated with parents dying from AIDS.

### **5.3.5 Community support and male involvement.**

Volunteers were probed about community support and male involvement in home based care activities and most of the volunteers said that the involvement of male and community is very low and suggested them to support and be involved in the home based care activities in their areas, this could be an indication that there is a low community support in caring for their patients.

The result relates with another study where it was found that in most of the African societies the care of the patients is mostly done by the women with an exception of few tribes which have their caring system where women are being exempted from caring for the men when it comes to a serious sickness (Ntozi 1997). The same study provided an example of Banyankole tribe from Uganda where women are excused from taking care of the male patients especially the adults except their husbands. In Malawi traditionally caring for the patients is a women task with a very minimum support from the men. In the same country most of the HBC volunteers were found to be women (Bacon et al 2002). Male involvement in the home based care is one of the major factors towards a better HBC program and it has been reported that home care programs can be cost-effective and sustainable when they bear community ownership and support of which can be reinforced by quality medical and social services from related stakeholders (FHI 2007). This could be due to the fact that in most of the African families men determines what is to be done and what not therefore men should be involved in caring for the patients so that they can realize the actual situation and hence influencing their decisions.

### **5.3.6 Prevention programs**

Most of the prevention programs such as those advocating condoms use, behaviour change and HIV education were reported to be existing but it was further added that the programs are mostly carried out in the urban areas and in the townships in peri urban areas, therefore the prevention program are not reaching the deep remote areas.

This has a long term impact on the HBC programs since it would jeopardise the efforts put by the programs if there will be an increase in the number of patients in the rural areas. The study found out from both volunteers and the organisations leaders that most of the prevention programs are working in the urban and peri urban areas leaving the rural communities without valid HIV/AIDS prevention programs.

The results concurs with the study from Ntozi (1997) where it was reported that there are fewer institutions in the rural area which deliver HIV/AIDS information, education and communication programmes of which make prevention materials not accessible in the rural areas. This gives a clear indication that most of the people in the rural areas are lacking HIV prevention education and prevention materials.

### **5.3.7 Program funding in relation to workload and sustainability.**

Adequate and consistent funding contributes greatly to a successful HBC program, the study found out that the level of funding is inadequate and it is characterized by high funding gaps.

Most of the organisation 62% remarked that the level of funding does not match with the planned activities either the number of clients in need of the services is higher and escalating everyday as in comparison to the level of funding. All organizations reported that there is a regular delay of funds from the donor hence hindering the planned activities as required of which worsen the level of HBC services provision.

These programs are also lacking other internal and external donors' support hence creating dependence on "Hope" programme funding. Most of these organisations also added that they are getting little funding for caring orphans and Vulnerable children (OVC) care and support. The volunteers added that OVC support has been very minimum than expected and some of the volunteers said a big number of OVC were just registered and have not realised any benefit from the program. This gives a picture that these organisations are carrying a large workload of patients that they cannot satisfy.

Most of the HBC organisations studied have shown a very limited local resources pooling ability hence reflecting a high donor dependency of which raises a concern about home based care programs continuity in case of donor withdrawal.

HBC programmes which depend on external support have limitations which include poor organizational management skills lack of adequate funding and technical support to sustain the project when the donor pulls out, poor targeting of support and where the programme is faith based there is a possibility of discrimination against non-faith members (UNAIDS 1999).

## **5.4 Factors associated with volunteers**

Different factors around home based care volunteers also determine the provision of HBC services. The emerging volunteers factors are age, sex, education level, HBC training, workload and personal responsibilities.

### **5.4.1 Volunteer's age and sex**

Volunteers' age was found to be lying between 20 and 50 years with the majority of them been between 30 and 40 years and 3 volunteers were above 50 years. These are matured adults who can take or handle the demanding role of caring for the patients and face the challenges of caring for the patients. The results are different from another study where some of the volunteers were small girls (Akintola 2004).

The sex distribution of the volunteers from the eight organizations surveyed was 43% and 57% for male and female volunteers respectively. The age and sex of the volunteers can have a great impact on the HBC services provision. An old volunteer would not be able to ride a bicycle or walk to reach far distance patients. Also adults or old patients can not be comfortable to be nursed or share sensitivity issues like sexual transmitted diseases (STDs) with a very young volunteer. Further studies should be carried to find out whether patients are much more comfortable to be cared by the same sex volunteer.

### **5.4.2. Volunteers level of education**

It is envisaged that some one who has attained a higher level of education has increased the knowledge and skills to easily grasp health education information and can communicate the information easily. Most of the volunteers were found to be having primary education, this call for the HBC programs which have volunteers with this level of education to consider providing regular refresher training and field supervision so as to ensure quality of the services being provided.

### **5.4.2 HBC Training to volunteers**

As in regard to HBC training all the volunteers were found to have attended a one month training which aimed at empowering them in the HBC services provision nevertheless it is evident from the study that most of the volunteers are adults who have primary education and have not sat in class for many years.

The home based care training conducted to volunteers followed the national HBC training curriculum which covers a range of topics. This gives a questions on whether they could have grasped all the materials taught and be able to recall and put them into practice. Therefore the ability of the volunteers to perform could be influenced by their age and the level of formal education, this could pose some difficulties for them to recall and conceptualize all the materials trained.

#### **5.4.4 Volunteer's workload and personal responsibilities**

The study also found out that the average number of clients being served by volunteers varies from one organization to another. "Hope" HBC programs recommends 15 patients and 20 orphans per volunteer but the study found out that there are some volunteers serving more than 20 patients and 25 OVC as indicated in section 4.3.4

Volunteers were also found to be having their normal routine occupations which earn them living of which most of them were doing farming, small business or the combination of the two, very few were employed. Along with their normal activities the majority of the volunteers including those who said that they do not have feasible occupation particularly women were found to be having other responsibilities which include care for the children. The quality of HBC being provided could be influenced by the volunteers serving many clients than planned together with having other responsibilities. In order to reduce the workload and expand the services coverage the programs should consider recruiting more volunteers and put in place some strategies to maintain the existing ones.

#### **Conclusion**

To sum up, the study results indicate that there are internal and external organization factors and HBC volunteer factors that hinder the provision of HBC services in the country. Some of these factors indicate that the services are not available, not affordable and not acceptable. The results relates with those of Thiede et al (2007) where it was shown that the major factors that influence the provision of health care services can be grouped into services availability, affordability and acceptability.

## Chapter Six

### Conclusion and recommendations

*The chapter concludes on the major findings from the study and also gives some insight on the policy recommendations.*

#### 6.1 Conclusion

The study aimed at exploring the factors that influence home based care services provision in Tanzania context. This included comparing the availability of HBC services between rural and semi urban settings.

The quantitative data collection method using structured questionnaires was used to gather information on the factors that influence home based care services provision from the HBC providers in rural and semi urban areas from “Hope” HBC program in Tanzania.

The study has provided a fair overview of the factors that hinder HBC services provision in the Tanzanian context. However the results of this study can not be generalised due to study limitations underlined previously. Despite of the limitations it is still envisaged that the study has contributed to the knowledge around home based care services provision especially in the aspects that need improvement in order to bring about quality HBC services and equal access to these services.

The study findings and the recommendations put forward has provided an overview of the HBC areas which need to be considered during planning and policy making in order to enhance the services provision and in ensuring the HBC programs sustainability.

The study concludes that there are internal and external organization factors and HBC volunteers’ factors that hinder HBC services provision in the country. The major internal organization factors found include inadequate supply of HBC kits, lack of organizations capacity to solicit funds for the program and the lack of strategies to motivate the community volunteers.

The external organization factors found include unavailability of referral points for different services, poor access to HBC services resulting from distance, poor infrastructure hence higher costs to reach the service points.

Other factors include the low levels of donor funding, cultural factors such as traditional medicines and believe in witchcraft, self stigma and the lack of community support and male involvement.

The volunteer factors found are inadequate motivation to volunteers, workload and lack of refresher training to volunteers.

The study found out the available referral points are VCT, CTCs and other health facilities such as dispensaries and health centres, however access to these services is still a question at hand. Either nutritional and income support referral points are none existence in the HBC program areas.

It was also evident from the study that the volunteers are lacking supportive supervision from the supervisors who are the health professional from the government health facilities. This could be attributed to the fact that the health care system is lacking medical personnel and therefore these supervisors are busy with their normal activities and can not provide the intended supportive supervision to the volunteers.

As the study hypothesised, it was found out that people in the semi urban areas have higher access to HBC related services than those in the rural areas. Some of the reasons for this situation are the fact that some of the health care facilities and HIV/AIDS programs are mostly situated in the urban areas as in comparison to the rural areas. It could also be attributed to the poor infrastructures for example roads hence unavailability of transport and sometimes people in the poor rural areas can not afford the transport cost. This is evident that some patients particularly those who are bed ridden are denied access to the services since their conditions do not allow them to walk or get into the troubles of transport.

In overall the study concludes that home based care for the people living with HIV/AIDs in Tanzania is a new area and highly needed but it is hampered by factors established. To enhance the level of HBC services provision in the country the influencing factors found need to be resolved so as to improve HBC services in the country.

This need joint efforts between HBC stakeholder such as the government, donors and the community in order to be tackled.

## **6.2 Recommendations**

For the country to attain its sixth millennium development goal on combating HIV/AIDS and other diseases, policy makers and other health care stakeholders in the country should come up with appropriate policies and plans which promote HIV/AIDS patients access to health care services including HBC related services.

The stakeholders should work to improve health care facilities and to ensure that there is equal distribution of HBC related services especially VCT, CTCs and preventions programs between rural and urban areas.

It would be over ambitious to have VCT and CTCs in all the angles of the country due to various reasons including economical reasons but HBC stakeholders should consider putting in place mobile services, a temporary solution could also be to provide grant to poor PLHIV so as to supplement or support transport for the patients to get to VCT and CTC services.

Since home based care programs work under the concept of continuum of care where effective referral system is a key point, there is a need to develop a guideline that can assist the organisations in establishing functional referrals and linkages with other HBC stakeholders or related services in their districts and in the community as a whole.

HIV prevention programs should link with HBC programs so as to reduce infections which in turn would over burden the health care system and the HBC programs. The HIV prevention programs should be distributed fairly in all areas of the country rather than concentrating only in the urban or peri urban areas where there are favourable working conditions.

There should be a strategy that will enable programs and institutions to deliver HIV/AIDS information, education and communication programmes and providing testing and counselling for HIV/AIDS. This include investing more on HIV/AIDS information and education programmes in order to reduce HIV infection

When individuals affected by HIV progress into illness they become weaker and need more services including emotional and psychological support therefore there is a need to advocate for the establishment of peer groups support in all of the program areas so that all patients can get all these kinds of support.

To challenge the issue of stigma, the HIV and HBC stakeholders should put forward some strategies to counterfeit stigma and discrimination. One of the strategies is to involve the people living with HIV/AIDS and peer groups in getting their ideas through forums and discussions. Either there is a need to develop a higher level of AIDS education in the families affected, in the community and the country as a whole. This in turn breaks the roots associated with stigma and also encounter believe associated with witchcraft and HIV/AIDS as a whole.

The beliefs on witchcraft and traditional healing are seen to be hindering the efforts to fight HIV/AIDS, therefore the HIV/AIDS stakeholders should consider researching on the cultural factors hindering the efforts and how to tackle them.

Poverty reduction programs should collaborate with the HBC stakeholders and join force in reducing poverty by strengthening the households' income generating activities. This should go hand in hand by empowering women who are taking the biggest challenges of HIV/AIDS in the families by deliberately putting in place economic strengthening programs that focus on women. Also the objective set by other local and international organisations on empowering rural livelihood should also be fulfilled.

To sustain HBC activities the government model of providing HBC should merge with the NGOs model, this enables availability of wider range of services and personnel. Also there has to be some deliberate efforts to build the capacity of these organizations in soliciting funds and in mobilizing the community so that they can own and contribute towards HBC activities. The HBC organizations should be trained on programs development and management so that they can access different funding rather than depending on funds from one donor. For the HBC programs to continue there is also a need to sensitize the community and the government to support HBC activities.

Communities have their traditional ways of helping one another for example through the small Christian communities.

Therefore the HBC programs should capitalise on the existing mechanisms to promote community HBC programs participation and ownership. Communities should be involved in activities that support HBC activities such as community farms that can supplement food for the patients; they can also give emotional encouragement and material support to the patients.

Since the study shows that patients and their families expect much from the volunteers, the programs should mobilise both community efforts and their efforts and put together in their plans. Failure to do this, the community may undermine their contribution in favour of the HBC programs efforts hence hindering community participation and HBC sustainability as a whole, therefore there should be a strong community supportive initiatives.

On the issues of male involvement the programs should make deliberate efforts to sensitise men to participate in HBC activities. Men should also be sensitized to care for the patient in their families as this reduces the burden of women in caring for the patients and also bring about gender equality and also influence the decision making in the issues related to care of the patients in the families. It is important to consider higher male involvement in caring for the patients in order to change the gender roles relation in the community and the families as a whole.

The HBC programs should strive to get their volunteers highly motivated through HBC refresher courses and where possible should consider providing more incentives which could be in terms of allowances, study tours and performance rewards. Other motivation to the volunteer's is to ensure adequate availability of working tools such as HBC kits. The government should consider supporting HBC programs with HBC kits, this can be done through exemption or subsidizing the cost for the HBC kits. Volunteers face different trauma in the course of caring for these patients, this is due to the fact that they face challenges which are out of their capacity, therefore volunteer just as the patients and their respective family members need some sort of psychosocial support. This could be in a form of group counselling or therapy after a certain period of time.

HBC organisations should support the volunteers in terms of field supportive supervision and care giving support since they need a continuous support and motivation. The lack of health professional to support the volunteers is an indication that the health sector is lacking health professional. This calls for the health care stakeholders to consider training more health professional particularly those who can supervise HBC activities. This facilitates the availability of HBC supervisors and hence a continuous supportive supervision to the volunteers.

The focus should also be to reduce the heavy dependency of the patients to volunteer for care by orienting the patients' family members so that they can assist in caring for their patients. For the volunteers to be able to do this they should be provided with refresher training and regular field supportive supervision on how to pass some of these roles to the family members.

To keep volunteers workload to a minimum, the programs should ensure transport is available to the volunteers for home visits and should consider adding more volunteers in order to reduce the workload and to serve more clients.

Lastly, for appropriate policies and planning around HBC services provision there is a need to carry out further studies which would also look at the government model of HBC since this study examined only the private organizations model of home based care

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**Appendix A: VOLUNTEER QUESTIONNAIRE**

**DETERMINANTS OF HOME BASED CARE SERVICES PROVISION**

**QES CODE** \_ \_ \_ \_

DATE OF INTERVIEW						
INTERVIEWERS NAME						
RESULT OF INTERVIEW: COMPLETE, LISTED INTERVIEWEE						1
INCOMPLETE, MIGRATED						2
INCOMPLETE, REFUSED						3
INCOMPLETE OTHER (SPECIFY) _____						4

**Socio-economic and demographic characteristics of the respondent/VOLUNTEER FACTORS: Circle the appropriate answers.**

NO	QUESTIONS	CODING CATEGORIES
1.	Age at your last birthday (Age in completed years).	<input type="text"/> <input type="text"/>
2.	Sex	Male.....1 Female...2
3.	What is your marital status now?	Never married.....1 Married.....2 Divorced.....3 Widowed.....4 Other (specify) _____
4	Have you ever attended school? (If No go to 7)	Yes.....1 No.....2
5	What level of education do you have?	Primary.....1 Secondary.....2 Tertiary.....3 Other (specify) _____
6	What is your occupation?	None.....1 Farmer.....2 Trader/Artisan.....3 Civil servant/Employed.....4 Other (specify) _____
8	What other responsibilities do you have (for a woman probe for maternal care)	1 _____ 2 _____ 3 _____

### HBC training, general knowledge about HIV/AIDS/VOLUNTEER FACTORS

9	Have you ever attended any formal HBC training	Yes.....1 No.....2																				
10.	From what source would you know that you have HIV/AIDS? Circle all mentioned	<table style="width: 100%; border: none;"> <thead> <tr> <th style="text-align: left; width: 50%;"><b>Spontaneous Responses</b></th> <th style="text-align: left; width: 50%;"><b>Probe Responses</b></th> </tr> </thead> <tbody> <tr> <td>Blood test (VCT).....01</td> <td>-----11</td> </tr> <tr> <td>Partner has HIV/AIDS...02</td> <td>-----12</td> </tr> <tr> <td>Had unprotected sex</td> <td></td> </tr> <tr> <td>With infected person...03</td> <td>-----13</td> </tr> <tr> <td>Consult a soothsayer...04</td> <td>-----14</td> </tr> <tr> <td>Symptoms.....05</td> <td>-----15</td> </tr> <tr> <td>Hear say.....06</td> <td>-----16</td> </tr> <tr> <td>From people trained as HIV/AIDS counsellors...07</td> <td>-----17</td> </tr> <tr> <td>Others (specify)_____</td> <td></td> </tr> </tbody> </table>	<b>Spontaneous Responses</b>	<b>Probe Responses</b>	Blood test (VCT).....01	-----11	Partner has HIV/AIDS...02	-----12	Had unprotected sex		With infected person...03	-----13	Consult a soothsayer...04	-----14	Symptoms.....05	-----15	Hear say.....06	-----16	From people trained as HIV/AIDS counsellors...07	-----17	Others (specify)_____	
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Symptoms.....05	-----15																					
Hear say.....06	-----16																					
From people trained as HIV/AIDS counsellors...07	-----17																					
Others (specify)_____																						
11	What is the main reason that all your patients have not gone for VCT/? (Circle all mentioned)	<table style="width: 100%; border: none;"> <tbody> <tr> <td>Financial/ transport to VCT centre.....1</td> </tr> <tr> <td>Do not know about VCT..... 2</td> </tr> <tr> <td>Avoid Stigmatization.....3</td> </tr> <tr> <td>VCT service not available around.....4</td> </tr> <tr> <td>Not necessary.....5</td> </tr> <tr> <td>Others (specify)_____</td> </tr> </tbody> </table>	Financial/ transport to VCT centre.....1	Do not know about VCT..... 2	Avoid Stigmatization.....3	VCT service not available around.....4	Not necessary.....5	Others (specify)_____														
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VCT service not available around.....4																						
Not necessary.....5																						
Others (specify)_____																						

### Services provision/HBC SITUATION/VOLUNTEER FACTORS

12	How many patients are you seeing now?	1. (1-5) 2. (6-10) 3. (11-15) 4. (16-20) 5.(21-25)
13	How many OVC are you seeing now?	1..... (1-5) 2..... (6-10) 3..... (11-15) 4..... (16-20) 5..... (21-25)
14	What means of transport do you use to reach the further distant patients	Bicycle.....1 Walking.....2 Others (Specify)_____
15	Do you promptly get the support from your supervisor/organization when you have a problem with your patients? (If yes go to 18)	Yes.....1 No.....2

16	If no what are the reasons?	<hr/> <hr/> <hr/>
17	<p>Which services are you providing and how do you rank their level of provision/support as in regard to what was taught in HBC training? (Circle all appropriately)</p>	<p>1)Nutritional support .....1.Enough, 2.Moderate, 3.Not enough  2)Income support.....1.Enough, 2.Moderate, 3.Not enough  3)Emotional/social support.....1.Enough,2.Moderate, 3.Not enough  4)HIV/AIDs education family carers....1.Enough, 2.Moderate, 3.Not enough  5)ARVs (who qualify).....1.Enough, 2.Moderate, 3.Not enough  6) Opport. Infections treat.....1.Enough, 2.Moderate, 3.Not enough  7)Referrals to CTC(VCT)....1.Enough, 2.Moderate, 3.Not enough  8)Referrals to VCT.....1.Enough, 2.Moderate, 3.Not enough  9)Clinics and Hospitals.....1.Enough, 2.Moderate, 3.Not enough  10)Spiritual counselling.....1.Enough,2.Moderate, 3.Not enough  11)Palliative care.....1.Enough, 2.Moderate, 3.Not enough  12)Supplies(e.g. soap, antiseptics)...1.Enough, 2.Moderate, 3.Not enough  Others_____</p> <hr/> <hr/>
18	<p>Do you always have equipped HBC kit? (Yes go to 21)</p>	<p>Yes.....1  No.....2</p>
19	If no what are the reasons?	<hr/> <hr/> <hr/>

20	Do you have legal support point in your area where your patients can be referred for legal issues such as wealth inheritance and other human rights?	Yes.....1 No.....2. Comments on how do you handle legal issues? _____ _____
21	Of the patients who are on ARVs; are the family members participating in ensuring that their patients adhere to the treatments?	Yes.....1.No,.....2 If no what are the reasons? _____ _____
22	Could you refer all of your patients who needed different referral?	1.VCT Yes.....1 No.....2 If no Comments _____ 2. CTC/ARVs Yes.....1 No.....2 Comments _____ 3. IGAs /Income support Yes.....1.No.....2. Comments _____ 4. Nutrition /Food Yes.....1.No.....2. Comments _____ 5. IO treat. Yes,.....1.No.....2 Comments _____ 6. Clinic and hosp. Yes.....1 No.....2 Comments _____ 7. Legal services Yes.....1.No.....2 Comments _____ Others _____

### External factors/Support

23	Referrals points in the working area; Districts/program area; if available and accessible e.g. VCT, CTC, IGAs, Nutrition support	Referral	Avail.	Comments i.e. If accessible, distance.	
				Distances	If Cost involved
		1.VCT			
		2.CTC/ARVs			
		3.Nutrition support			
		4.IGAs support			
		5. IO treat.			
		6.Clinics and hosp.			
		7.Legal support			
		8.Emotional/social support			
		9. Spiritual			
		Others			

### Challenges

24	What are the main reasons that some of your patients who qualify to be on the ARVs are not getting them?	Financial/ transport to CTC/ARV Clinic.....1 Do not know about ARV.....2 Avoid Stigmatization.....3 ARV services not available around.....4 Not necessary.....5 Other (specify)_____
25	Do males participate in the home care of the patients	Yes.....1 No.....2 If no what are the reasons? _____
26	What makes you happy working as HBC volunteer?	_____

27	What is the hardest part of your work as the volunteer?	_____
28	What is in the community that hinders HBC activities?	_____
29	Do you collect all the required data for reporting correctly and timely as required?	Yes.....1 .No.....2 Comments_____

**SECTION 5: Motivation and incentives**

30	During the meetings with the organization are you given time to air out your problems, views or suggestions?	Yes.....1 No.....2 Comments_____
31	What kind of motivation do you get from working as a volunteer?	Some allowance.....1 Just happy to offer the service.....2 No motivation.....3
32	If you get some allowance, do you get it on time?	Yes.....1 No.....2
33	If there were another HBC programmes in your area, which provides higher incentives/allowances than where you are now, would you prefer joining it?	Yes.....1 No.....2
34	Do you get any referral support i.e. from the supervisor/community?	Yes.....1 No.....2 If no what are the reasons? 1. Distance to the referral points, 2.Lack of referral points, 3. Staff in the referral points not corporative. Other specify_____
35	What keeps you volunteering?	1.Religion/Faith 2.Some allowances 3. Urge to help Others (Specify)_____
36	On you own opinion what do you think should be done in order to improve the quality of HBC services provision in your area	1_____ 2_____ 3_____ 4_____

Thank you for your time

**Appendix B: NGO LEADERS' QUESTIONNAIRE**

**DETERMINANTS OF HOME BASED CARE SERVICES PROVISION**

**QES CODE** \_ \_ \_ \_

DATE OF INTERVIEW						
NAME OF THE NGO						
INTERVIEWERS NAME						
RESULT OF INTERVIEW:COMPLETE						1
INCOMPLETE						2
OTHER(SPECIFY)_____						3

**SECTION 1: Organization FACTORS      Circle the appropriate answers.**

NO	QUESTIONS	CODING CATEGORIES
1	For how long has your organization been providing HBC services?(Years/months)	_____
2	How many patients is your organization serving currently?	Total_____ Male_____ Female_____
3	How many OVC is your organization serving currently?	Total_____
4	How many volunteers do you have?	Total_____ Male _____ Female_____
5	Do you have any staff with medical/clinical related education background?	Yes.....1 No.....2
6	If yes give the details of the course	_____ _____
7	Do you have any staff with formal HBC training?	Yes.....1 No.....2
8	If yes give details of the training	_____ _____
9	How many staff has left your organization since the inception of Hope HBC programme?	_____
10	What were the reasons for their withdrawal?	_____ _____

11	How many Volunteers have withdrawn from working with your HBC programme since the inception of Hope HBC programme?	_____
12	If any, what do you think are the reasons for their withdraw or drop out?	_____ _____
13	What do you think is the main drive for your Volunteers to work as HBC carers	1.Religious faith 2. Incentives/Allowances 3.Drive/spirit to help others 4.Other expected benefits; i.e. training
14	Do you have other donors funding your HBC program out of Tumaini?	Yes.....1 No.....2 If yes mention them_____
15	Level of funding by Tumaini	1.Enough, 2.Moderate, 3.Not enough
16	Do you regularly hold informal meetings where you discuss the implementation plans?	Yes.....1 No.....2

**SECTION 2: HBC services provision/HBC SITUATION/Reporting**

17	Do all of your volunteers always have equipped HBC kits/Supplies. (Yes go to 26)	Yes.....1 No.....2
18	If no what are the reasons	_____ _____
19	What are the main reasons that make some of your patients not getting services e.g. ARVs	Financial/ transport to CTC/ARV Clinic.....1 Do not know about ARV.....2 Avoid Stigmatization.....3 ARV services not available around.....4 Not necessary.....5 Other (specify).....6
20	Are there prevention programs in your programme area e.g. PMTCT, Condom programme?	Yes.....1 No.....2 If no give reasons_____

21	Do the HBC volunteers collect all the required data for reporting correctly and timely as required:	Yes.....1 No.....2 Comments_____
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### SECTION 3: Referrals.

22	Are all of your patients been referred for different services as required?	Yes.....1 No.....2				
23	Referrals points in the working area; Districts/program area; if available and accessible e.g. VCT, CTC, IGAs, Nutrition support	<b>Referral</b>	<b>Avail.</b>	<b>Comments i.e. If accessible distance.</b>		
				<b>Distances</b>	<b>Cost</b>	
		1.VCT				
		2.CTC/ARVs				
		3.Nutrition support				
		4.IGAs support				
		5. IO treat.				
		6.Clinics and hosp.				
		7.Legal support				
		8.Emotional/social support				
9. Spiritual						
	Others					

### Motivation and relationships

24	How do you rank the working morale/motivation of your volunteers?	1. High. 2. Average 3. Low Reasons for the above_____
25	Do you give feed back/progress reports to your volunteers on regular basis?	Yes.....1 No.....2 If Yes how regular? _____
26	Out of the little allowance provide to your volunteers what else do you do to get them motivated?	_____

Thank you for your time

## Appendix C: Volunteers/NGO leaders consent form

Consent form for the study on determinants of Home based care services

I am **Paul Mahunga**, a student studying for Masters in Public Health at the University of Cape Town. I am collecting information for the study on the factors that determine home based care services, these include organizational factors, external factors and home based care volunteers factors. The study is also seeking information on the availability of HBC services between rural and peri-urban settings.

I, therefore request for your consent to interview you as in regard to the above stated aims.

The participation in this study is voluntary and you may choose not to participate. Whatever information to be collected will not affect the home based care services that is being provided and will not be given to anyone else except for the purpose of this study which aims at improving the HBC programmes.

Do I have your permission to continue with the questions?

Yes  No

Name (Volunteer)/NGO leader: \_\_\_\_\_

Signature (Volunteer): \_\_\_\_\_ Date: \_\_\_\_\_

Name (Witness): \_\_\_\_\_

Signature (Witness): \_\_\_\_\_ Date: \_\_\_\_\_