THE CHALLENGES OF THE COMMUNITY VOLUNTEERS IN THE PROVISION OF HOME BASED CARE TO HIV/AIDS PATIENTS IN MBEYA MUNICIPALITY.

BY

DR.PETER M GEMBA

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P. O. Box 65001
DAR ES SALAAM

CERTIFICATION.

The undersigned certifies that he has read and hereby recommends for acceptance by the University of Dar es Salaam a dissertation entitled: *"The challenges of Community Volunteers in the provision of HBC to **HIV\AIDS** patients in Mbeya Municipality'' in* partial fulfillment of the requirement for degree of Master of Public Health.

DR M A Mwangu. (B.A. Ed. M.A. PHD.)

(SUPERVISOR).

Date.....7th NOV. 2005.....

DECLARATION.

I, Peter Mchuno Gemba, declare that this dissertation is my original work, and that it has not been presented and will not be presented to any other university for similar or any other degree awards.

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DEDICATION

I dedicate this work to the memory of my late father Bernard Mchuno Gemba, my mother Catherine Tarmo Gemba, my Wife Restituta Allois Gemba and my children; Catherine, Bernard, Barnabas and Maria.

ABSTRACT

In response to the impact of HIV/AIDS pandemic on the Health Sector, governments have adopted the Home Based Care strategy for PLWHA.

A descriptive cross-sectional study to determine the challenges of the Community Volunteers providing HBC to PLWHA was conducted in Mbeya Municipality in June 2005. The aim of the study was to determine the constraints or problems encountered by community volunteers in providing services to HIV/AIDS patients, in order to recommend ways and means to improve quality of HBC services.

The findings of the study have shown that majority of the community volunteers 68.8% were women; 74.0% are primary school leavers and most of them 83.8% are not employed. The main problems found included lack of salaries, no transport, inadequate skills and knowledge, inadequate supplies, poor community support and stigma. From the findings of this study, it is evident that community volunteers providing HBC services to HIV\AIDS patients in our societies face tremendous challenges most of which are beyond their capabilities to solve.

Considering the importance of HBC to HIV\AIDS patients; the study recommends that the government in collaboration with all organizations providing HBC to HIV\AIDS patients, workout a policy stating clearly the remuneration of a community volunteer. Streamlining HBC services provided by community volunteers into the Comprehensive District Health Plans may provide needed solutions to problems like salaries, transport,

supplies and training, which address their needs. Access to uniform package for community volunteers regardless of where they are geographically or under which organization they are, will motivate them and increase the quality of care to their clients.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
AMREF	African Medical Research Foundation
ARV	Anti Retroviral
CBO	Community Based Organization
CCBRT	Comprehensive Community Based Rehabilitation and Treatment
CHBC	Community Health Based Care
DANIDA	Danish Development Agency
DCC	Dar es Salaam City Council
DHMT	District Health Management Teams
GTZ	Gesellschaft fur Technische Zusammenarbeil (German International Technical Cooperation)
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
HW	Health Workers
ICASA	International Conference on AIDS and STIs for Africa
ICHBC	Integrated Community Home Based Care
IDC	Infectious Diseases Centre
MOH	Ministry of Health
NACP	National AIDS Control Program
NGO	Non Governmental Organization
NMSF	National Multi-Sectoral Framework

OI	Opportunistic Infections
PASADA	Pastoral Activities and Services for people with AIDS Dar es Salaam Archdiocese
PLWHA	People Living With HIV/AIDS
TACAIDS	Tanzania Commission for AIDS
UNAIDS	Joint United Nations Program for HIV/AIDS
UNDP	United Nations Development Program
WAMATA	Walio katika Mapambano ya Ukimwi Tanzania
WB	World Bank
WHO	World Health Organization

CHAPTER ONE

1.0 Introduction

1.1 HIV/AIDS, global overview

39.4 million people are thought to be infected with HIV/AIDS worldwide. More than 20 million have died of HIV\AIDS, most of the deaths occurring in the developing countries. It is estimated 4.9 million HIV infections and 3.1 million deaths occur globally every year. 2.3 million deaths due to HIV\AIDS occur in Sub Sahara Africa alone (UNAIDS/WHO, 2004)

In many countries, hospitals cannot cope with the large numbers of people living with HIV/AIDS, so they often send patients home to be cared for in their communities (AIDS Action, 2000).

Governments in the developing world have therefore emphasized the adoption and development of Home Based Care (HBC) as one of the strategies to mitigate the impact of HIV/AIDS on the health system. HBC is expected to meet the expectations of the sick, families and the community. The task to provide the required HBC lies on the governments, non-governmental organizations, communities and civic organizations. This is important especially considering that HIV/AIDS is the leading cause of the Burden of Disease (BoD), accounting for about 6% of the burden globally (UNAIDS 2004).

The HIV/AIDS has affected poor countries more seriously thus making the global inequity in health care serious. About 70% of HIV/AIDS affected people globally are those living in Sub-Saharan Africa. (UNAIDS, 2004) It has also made the poverty in those countries worse. There is a gender inequity with women being affected more as compared to men. The main reasons for this include gender discrimination, socio-economic status, the greater effects of wars, and biological vulnerability (World Health Organization 2000).

The HIV/AIDS was first described in the early 1980s. In Tanzania the first three AIDS cases were reported in Kagera region in 1983. The first three cases were, however, followed by rapid spread of the pandemic, such that by 1986 regions of the Tanzania mainland had reported AIDS cases. In 2003, Tanzania mainland was estimated to have 1,820,000 people living with HIV (840,000 females and 960,000 males). A total of 176,102 AIDS cases have been reported from 21 regions since 1983 (NACP, 2005)

The main mode of HIV transmission in Tanzania was heterosexual accounting for over 90% of all new cases followed in magnitude by perinatal transmission whereby mother passes the virus to the child during pregnancy or at the time of birth or through breastfeeding (NACP, 2005). Other modes of transmission can be through infected blood, blood products donated organs or bone graft and tissues.

The Tanzania HIV/AIDS Indicator survey conducted in 2003-2004 in Tanzania mainland revealed an overall HIV prevalence of 7% ranging from 2% in Kigoma and Manyara regions to 13.5% in Mbeya Region (NACP, 2005). The epidemic is a serious threat to the country's social and economic development and has serious and direct implications on social services

1.2 HIV/AIDS and the health sector

In all affected countries the HIV/AIDS epidemic is bringing additional pressure to bear on the health sector. As the epidemic matures the demand for care for those living with HIV/AIDS rises, as does the toll among health workers. In Sub Saharan Africa the annual direct medical cost of AIDS (excluding antiretroviral therapy) have been estimated at US$ 30 per capita at a time when overall public health spending is less than US$10 for most African countries (World Bank, 1996).

Health care services face different levels of strain depending on the number of people who seek services the nature of their need and the capacity to deliver that care.

The World Bank estimated that in Tanzania an infected person would require over 280 days of care if one would add all sick days together, it will cost Tshs. 56,000 or US dollars 290 in nursing and drugs and a child would need a total of 200 days of care at a cost of Tsh. 37,600 or 195 US dollars (World Bank 1996).

Beside costs, HIV/AIDS results in excessive use of health resources. For example, in Tanzania reports from urban hospitals have shown that patients with AIDS occupy approximately 50 – 60% of the hospital beds. Thus at patient, family and community level, HIV/AIDS leads to loss of lives, loss of production and increased need and utilization of medical care (World Bank, 1996).

It has also been estimated that AIDS expenditure for care would currently absorb one quarter of the governments recurrent health budget, thus government will have to make difficult decisions regarding treating AIDS versus treating other illnesses (World Bank 1996). As a consequence HIV/AIDS has also brought with it new challenges of how to provide care and support unique to those who fall sick and surviving family members. HIV has added a great burden to a grossly under funded and already overstretched health sector, therefore likely to compromise the quality of health care provision.

At the same time as the demand for health care services is expanding, so more health care professional are being affected by HIV/AIDS. For example, Malawi and Zambia are experiencing a 5-6 fold increase in health worker illness and death rates thus increasing workload and stress to the remaining workers (AIDS Action, 2000).

To mitigate the HIV/AIDS impact on the health system; governments have adopted among other strategies, promotion of Home Based Care (HBC). This study was

prompted by the need to know the challenges and needs of Community Volunteers in providing Home Based Care in an effort to promote quality of care for HIV/AIDS patients.

1.3 Statement of the problem

The HIV/AIDS pandemic has greatly increased the demand for health care, for example in Tanzania, reports from urban hospitals show that patients with AIDS occupy approximately 50%-60% of the hospital beds (World Bank 1996).

In response to HIV/AIDS impact on the health system, governments have adopted among other strategies, promotion of Home Based Care (HBC) for HIV/AIDS patients.

However, many people providing this care are not professional careers or health workers, but are volunteers, family members or friends. Although much of the literature talks about "coping strategies" the reality is that in many communities, care providers are struggling to cope with the enormous need for care and the lack of resources, support and training needed to provide it (AIDS Action, 2000).

There is however insufficient information on the situation in which the community volunteers are providing HBC services to HIV/AIDS patients in Mbeya. This study

was aimed at identifying the challenges and needs of the community volunteers in providing HBC to HIV/AIDS patients in Mbeya Municipality.

1.4 Rationale

Tanzania responses to the HIV/AIDS include the establishment of Tanzania Commission for AIDS, National Aids Control Programme, and National Multi-Sectoral Frame Work (NMSF). The NMSF spells the strategies for mitigating the epidemic; this includes HBC services for HIV/AIDS patients.

The results of this study will provide information on the challenges and needs of the community volunteer providing HBC to HIV/AIDS patients for improving quality of life PLWHA.

1.5.0 Literature review

1.5.1 HBC in Tanzania

On searching for alternatives that can efficiently serve the needs and improve the quality of life of PLWHA, the Ministry of Health through DANIDA support established a Home Based care (HBC) model in 1995 in pilot districts. The model extended care from the health facilities to the community, households and to families. The support consisted of drugs, supplies, bicycles and equipment to eight Districts in Coast and Rukwa Region.

One year later the MOH and Gesellschaft fur Technische Zusammenarbeil (GTZ) (German International Cooperation) also established a program for counseling and HBC in Mbeya Region .The main aim was to answer the needs of HIV/AIDS infected patients and their families at a reasonable cost (MOH, 2003). Within this program in 1996 three hospitals started to provide HBC (one mission and two public), in their model of HBC they planned one visit to PLWHA once every week or more frequent depending on the patients needs and their family.

All HBC initiatives provided a Kit to areas after training a provider and the family. An evaluation was done later and it was revealed that most of the clients were satisfied. In addition other benefits included the observation that HBC services were closer to the communities and which also enhanced the acceptance of persons living HIV/AIDS.

The results influenced the decision that it was important for HBC to be included within District Health Plans all over the country (MOH, 2002). This would result to HBC integration into District Health Care delivery system, promotion and strengthening the continuum of care for PLWHA from health facilities to their families.

Expansion and coverage of HBC has been increasing from time to time. In December 1999 WHO provided drugs, supplies and equipments to Tanzania for general care of

HIV/AIDS patients. This donor support strengthened the continuity of HBC services at district level. Later in 1999/2000 UNDP provided an enabling support to extend HBC to Shinyanga and Kigoma regions. Another development partner support was realized in July 2001 when Tanzania was selected among 10 African Countries to benefit from an Italian Initiative for the Fight against AIDS in Africa aimed at strengthening of Community Based Care services in 11 Districts in Tanzania mainland and Zanzibar. Through this support HBC providers have been trained, medicines and resources for HBC have been supplied, communities have been made aware of the services and clients are being cared for in the participating Districts (MOH, 2003).

The 2003-2006 Health Sector HIV/AIDS strategy for Tanzania recognizes care and support as a critical component in the response to the epidemic. Currently there are several groups providing HBC in the country. In Dar es Salaam there is CCBRT, PASADA, Pathfinder International, AMREF, WAMATA, IDC, and MUCHS. (MOH, 2003)

The National Aids Control programme (NACP) strategy envisages that about 5,000 people will be receiving HBC by the year 2006, this is a very small number compared to a total of 1,820,000 people living with HIV and 176,102 AIDS cases that has occurred since the beginning of the epidemic in Tanzania (NACP, 2003).

It can then be concluded that HBC for HIV/AIDS is still at its formative stage. More important is that, there are many stakeholders both foreign and local with different interest and capacities. Home Based Care is now reported and acknowledged as the most appropriate way of responding to the ever-increasing problems and needs of the chronically ill due to HIV/AIDS and other causes. The aim of this study is to assess the current needs of the community volunteers providing HBC to HIV/AIDS patients and the constraints they encounter in the process of providing the care

1.5.2 Home Based Care Needs

Globally it is estimated that about 40 million people are HIV infected (UNAIDS/WHO, 2004). In Tanzania it is estimated that 1,820,000 people are currently HIV positive (NACP, 2003), among these less than 5000 patients are under HBC Tanzania (MOH, 2003).

A study done in Nairobi has shown an insufficient number of providers are involved in HBC due to stigma that is still attached to people living with HIV/AIDS; however there are many people in need of these services. The study findings suggested the need to move from awareness creation to assisting the suffering through HBC (Amisi, 2003). It is then clear that meeting the needs of those patients is very challenging.

Many people living with HIV/AIDS feel isolated and alone; often the people closer to them feel hopeless and overwhelmed. The medical and social services systems are

unknown to those most needing them (UNAIDS, 2004). The needs are also defined by the morbidity conditions like diarrhea, nutrition, and ulcers. HIV/AIDS run a chronic course, patients becoming progressively disabled. They need legal, moral and psychosocial support. Therefore PLWHA who are under HBC would require a combination of intervention to meet their needs.

Medical needs are determined by the stage in the natural history of the disease, and types of morbidity. In meeting these needs, the most important thing would be the provision of HBC kit that contains medicines and supplies for treatment of opportunistic infections and prevention of HIV transmission to others. The importance of human resources that is skilled on HBC, as well as finance for allowances, transport, and for purchasing necessary equipments for HBC services cannot be overemphasized (Pathfinder International, 2002).

Apart from the health care needs, the patient and family would need spiritual support and counseling from religious leaders, psychosocial support from relatives, friends, neighbors and significant others, as well as supply of safe water and proper basic sanitation. The patient also needs legal support, accessible and affordable housing, disinfectants and equipments like gloves, gauze, bandages, and mackintosh (MOH, 1999).

The disease runs a chronic course with very high demand on the patient's nutrition. There is also inadequate food intake resulting to rapid deterioration of the patients' physical condition. Provision of adequate nutrition is thus a critical component of AIDS case management. There is a need for collaboration with other sectors which deals with food production while giving education to patient and family caregivers about nutrition supplementations using locally available foods (MOH, 2003).

Political commitment and continued support is crucial for the success and sustenance of HBC. At the National level, Policy makers and politicians should address issues favoring HBC. There should be Multi-Sectoral and International collaboration on poverty eradication, employment opportunities, woman empowerment, support on the vulnerable groups such as orphans, children living in the streets and drug abusers (MOH, 1999).

The Pathfinder International CHBC conducted a baseline and needs assessment survey in Dar es Salaam. The aim was to generate information to guide the CHBC programme and determine areas of focus in designing and implementation of CHBC services and training. The findings were that; only 7% of the respondents reported to have had access to HBC services. About satisfaction from HBC providers 40% needed more home visits, 28% required guidance on treatment and counseling, 16.7% needed incentives for caregivers, 14% said they would appreciate any kind of HBC given. Regarding chronically ill respondents, 22.5% would like free medicines to

given. Regarding chronically ill respondents, 22.5% would like free medicines to treat opportunistic infections, and regular medical check-ups, 10.1% needed HBC services, 9.8% needed financial support and 8.9% needed food supply. Almost a half of the respondents stated that they didn't know their needs. Seven out of ten households caring for an ill patient expressed that they experienced nutritional problems including lack of money to purchase food, access to only one meal per day, having no one to cook for them, and loss of appetite of the patient. The main source of care and support was from distant family members (57%), neighbors and friends (17%), Local Catholic Church (Kigamboni) (70%), PASADA (7%), CCBRT (5%) and Kiwohede (2 %) (Pathfinder International, 2002).

1.5.3 Models of HBC

There are many stakeholders in the provision of HBC and similarly there are several HBC models that could be influenced by the provider. Analysis of 67 home based care program in Zimbabwe had been very informative on this (Woelk et al., 1997). The analysis revealed information on minimum package and type of HBC design by what they provided. Most HBC types included financial assistance to patients and caregivers, provision of gloves bleach and medical supplies, visiting patient within one week after discharge. Other contents of HBC included having full-time trained health worker, more frequent visits to seriously ill patients, volunteers receive structured training, access to as many health care supplies and access to as much food supplies as required by the patient.

It can then be concluded that there is variation in the ways HBC services are meeting the needs of the PLWHA. Also there is variation in the satisfaction with care providers. The provider and type of HBC could also influence the satisfaction. In Tanzania there are several modalities of HBC delivery. The Ministry of Health has adopted the following model of HBC services delivery: -

i. Hospital or facility based outreach using HBC provider.

ii. NGOs-based using employed personnel.

iii. Community rooted using community volunteer.

iv. PLWHA frontline Health care networks. This is a HBC provision by patients together with their families with strong focus on supportive and spiritual care (MOH, 1999).

These modalities provide a level of care that is quality wise acceptable, and being cost-effective. Each modality has its advantages and disadvantages but the prime quality is the shared responsibility between institutions and communities. However success and sustainability of HBC will depend on the cost at the family and health facility levels, appropriate administration, logistics and supplies Economic

If these needs are achieved, then HBC services will be able to improve the quality of life of the PLWHA.

1.5.4 Benefits and constraints of HBC

The benefit of HBC services includes; improved health of the patient, identified needs to the community, and breaking stigma. Improved health of patient is evaluated both from the patients and providers perspectives. It includes description of positive changes witnessed among patients. It requires availability of correct interventions and has one in place to make sure the patient take their medication and following up trivial changes before they become a serious health risk. Patient on the other hand also appreciates that their needs are met and don't have to travel long distance to a clinic (National Department of Health, 2002).

Community needs could include having the structures in place that will facilitate identifying needs of clients and referral. It will also enable caregivers living in communities to identify people with needs and problems through social networks and bring them to care providers. A formal communication infrastructure often doesn't exist. Therefore establishing HBC will to a large extent facilitate establishing those structures.

Stigma has been a setback in the control of HIV/AIDS epidemic. Caring of patients in their homes is a means of breaking the cycle of fear surrounding the terminal illness. The HBC also increases visibility of PLWHA in the community thereby encouraging the normalization of the virus, discussion and understanding.

This also benefits both family and community between in some instances patients have requested that caregivers meet them outside their homes or leave their medicine at a nearby shop. HBC will also reduce misconception about palliative care because caregivers are seen as bringing death to the household. (National Department of Health, 2002). The implementation of HBC is still facing some constraints, despite the fact that HBC has been acknowledged in various studies; there is lack of common understanding of the concepts of home and community care at all levels, even by stakeholders.

There is also inadequate number, support, and integration of HBC service providers from hospital and Districts Health Management Teams (DHMTs). Stigma that is still attached to HIV/AIDS hinders the counseling process, care and support of these patients (MOH, DCC/CCBRT, 2002). Lack of access to basic nutritional needs makes it difficult for patients to comply with medication given. It also exacerbates attack of opportunistic infections and death to PLWHA.

Notwithstanding the benefits and constraints there have been efforts to objectively establish cost-effectiveness of HBC. In 1998 an operational research on cost effectiveness of HBC services and other factors affecting its impact on chronically ill patients due to HIV/AIDS was conducted in Bagamoyo district. The main focus was on total time spent with patients, distance traveled to see patients, and drugs used; this study revealed that the average cost of HBC was Tshs. 1,862/= per day for the

community located volunteer, Tshs. 2,443/= per day where HBC was provided by a health worker. An average hospital based care was estimated to cost tshs. 4,921/= per day at Bagamoyo hospital (Msumi Z, and Musobi N, 2000)

Guided by the information on HBC being cost-effective a decision was reached that by February 2002 HBC services had to be established in 28 districts in the 6 regions. Also a total number of 102 HBC trainers had to be trained in those districts (MOH, 2002).

On the contrary some other studies have not been able to document significant cost-effectiveness of HBC. A study done in Zimbabwe on costs and quality of home-based care for HIV/AIDS patients (Woelk, et al., 1997, Hensen, et al, 1998) revealed that the model of care was not significantly cost-effective. In any case however hospital and home-based care should complement each other, rather than substitutes for the other. It has also been cautioned that HBC may not necessarily be much cheaper than models relying more intensively on hospital based (especially if frequent home visits are considered a necessity). HBC should thus be considered an extension of the health system to communities and families. However, no one has ever given value to patient's wishes to die at home and the comfort realized from being with relatives and with familiar environment. There is also no sufficient information to conclusively compare home and hospital based care for HIV/AIDS patients. In the Zimbabwe study since the clinical outcomes and quality of life of patients in the two models

remains unclear, thus justifying the need of more detailed and bigger studies to evaluate HBC in resource poor countries (Woelk, et al., 1997).

In conclusion, HBC services should be considered as a complement to hospital services and ensure that it meets the needs of PLWHA by improving their quality of life regardless of how cheaper or expensive it can be. There should be community sensitization and multi-sectoral approach to assist the HIV/AIDS suffering through HBC support and funds mobilization. This study will also generate information on the challenges and needs of the community volunteer providing HBC

1.6.0 Definition of words / terms

Some of the terms and words used in this dissertation need to be defined as their meanings may vary from one situation to another depending on socio- cultural background, work experiences, and geographical location.

1.6.1 Home base care (HBC)

Can be defined as any form of care given to patient with HIV/AIDS or patients with chronic illness in their own home and community. It can be activities that a patient living with HIV/AIDS (PLWHA) might do to take care of him or herself or care given by their relatives, friends or health workers within their homes and community.

HBC is meant to maximize and utilize the existing available resources within the community while family and community participate is taken as a basic component in providing such care (MOH, 1999).

1.6.2 Quality

Is a measure of how good something is, or the degree of excellence or superiority that a thing posse's. A service is said to be of quality if it meets or exceeds the expectations of the user.

1.6.3 Quality of life

Overall enjoyment of life that is; an ability to perform various tasks

1.6.4 Quality of care

The degree to which health care services for individuals and population increase the likelihood of desired health outcomes and are consistent with current professional knowledge.

1.6.5 HBC provider

Is any person or a group of people that provides health care services to the patients within their home following standards that have been set (MOH, 1999).

1.6.6 Chronically ill HIV/AIDS patient

Is the patient who continues to be ill for more than one month, such patients include those with the disease that take long to be cured or those of life long like HIV/AIDS

1.7.0 Study Objectives.

1.7.1 The Broad Objective

The broad objective of this study was to determine the needs of community volunteers in providing sustainable and quality Home Based Care for HIV/AIDS patients

1.7.2 Specific Objectives

i. To determine the Socio- demographic characteristics of community volunteers that provides HBC by age, sex, educational level and occupation in Mbeya Municipality.

ii. To identify different groups supporting community volunteers in providing HBC in Mbeya Municipality.

iii. To identify the types of HBC provided by community volunteers to HIV/AIDS patients in Mbeya Municipality.

iv. To identify the constraints encountered by community volunteers while providing HBC to HIV/AIDS patients in Mbeya Municipality.

v. To propose ways and means of improving and sustaining HBC services to PLWHA using local resources.

vi. To disseminate the results of the study to the relevant authorities for possible actions towards improvement.

CHAPTER TWO

2.0 Methodology

2.1 Description of the Study area

A descriptive cross sectional study on the challenges of Community Volunteers providing Home Based Care to HIV\AIDS patients was conducted in Mbeya Municipality from 15th of June 2005 to 30th of June 2005.

Mbeya region is situated on the south west of the country. The region with a population of 2.5 million borders Zambia and Malawi. A major highway runs through Mbeya Municipality to join the two countries with Tanzania. People of the neighboring countries conduct border trade deep into each other country.

Mbeya is the highly affected region by HIV\AIDS in the country with a prevalence of 13.5% (NACP, 2003-2004). According to the 2004 regional report the there were 1265 new clinical cases of AIDS recorded between January and December 2004, throughout the region, 252 of these are in the Municipality. Number of PLHA in the region is 3519 out of which 431 were in the Municipality. (MRCP, 2004)

HBC services for PLWHA in the region were started since 1996 with the assistance of GTZ. Health workers through outreach program initially provided the services. However, due to increasing demand for service, community volunteers have been trained to provide HBC to HIV/AIDS patients in their communities. (GTZ, 2000)


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Mbeya region was chosen for this study due to the fact that it is the highly affected region in the country by HIV/AIDS, and due to the fact that the HBC services has been in place now for a reasonable period of time, and also because of resource limitation, the study was confine to Mbeya Municipality only.

2.2 Target population.

The target populations in this study were all community volunteers providing HBC to HIV\AIDS patients in Mbeya Municipality.

2.3 Study design

The study design was a descriptive cross-sectional study of community volunteers providing HBC to HIV/AIDS patients in Mbeya Municipality.

2.4 Sampling and sample size.

Non-probability convenient sampling procedure was used to obtain the study subjects. All community volunteers providing HBC in the study area, who were reached by the research team, during the study period where included in the study. Out of 186 reportedly active volunteers, 154 were interviewed, the remaining 32 could not be reached due to various reasons including sickness and traveling outside the Municipality. The response rate was calculated by dividing the total subjects interviewed 154, by the target population 186, giving a response rate of 82.8%.

2.4 Eligibility to participate in the study.

Participants to the study were only those community volunteers providing HBC to HIV\AIDS patients in Mbeya Municipality who voluntarily agreed to participate in the research. The purpose of the study was explained to the research participants before being asked to give their informed consent verbally.

2.5 Recruiting and Training Research Assistants

Four research assistants were recruited and trained for two days on how to use research instruments; the research assistants were also involved in translating the English questionnaire into Kiswahili. This was done to enable them to understand the insight of the questions and facilitate easy administration of the questionnaire to the respondents.

2.6 Research instruments

This study involved the use of interviewer-administered questionnaire. Information collected included the socio demographic characteristics of community volunteers providing CBHC i.e. age, sex, education, and occupation, types of HBC services provided by the community volunteers in their settings.

Problems encountered by the community volunteers when delivering care to the patients. Other information-included organizations, groups or individuals who provide support to the community volunteers, types of support provided to enable

community volunteers. Information was also collected on the volunteer perceptions of their needs in order to improve the quality of HBC services.

The Swahili questionnaire translated from the English version was used to collect information.

2.7 Pre-testing research instruments

Pre-testing of the questionnaire was done at Iziwa, a small settlement on the outskirts of the Mbeya Municipality two days before the study began. The questionnaire was pre-tested for clarity of questions, language used and to estimate time required to conduct an interview to one respondent. On the basis of the pre test, necessary modifications were made to improve it.

2.8 Data collection

Interviewer guided questionnaire was used to collect information from the respondents. The respondents, who were the community volunteers providing HBC to HIV\AIDS patients, were visited at home and some were traced to their work places with assistance from local leaders or a health worker from the nearby health facility.

Information was collected using questionnaire with both open and closed ended questions, each interview took about twenty minutes.

2.9 Data management and analysis

Data was collected on daily basis according to the study work plan. The researcher and the research assistants checked the data collected for completeness and accuracy on the same day. All information obtained was coded and then entered in a computer software program for cleaning and further processing. Epi Info version 6.04 was used for data analysis. Data on the socio demographic characteristics was analyzed focusing on reported constraints.

2.10 Limitations of the study

Due to financial and time resource limitation, this study was conducted in Mbeya Municipality only. Thus the results may not necessarily represent the general situation in the country.

2.11 Ethical issues

Ethical clearance was obtained from Directorate of Research and Publication Committee of the MUCHS. Permission to conduct the study was also requested and obtained from the Regional and the Municipal Authorities in Mbeya upon presentation of the letter of introduction from MUCHS. The consent of the study subjects was sought verbally from the research participants after explaining the objectives of the study. Research participants were assured that their participation in the study was voluntary, however, they were also told that results of the study might contribute towards improvement of the services their providing.

CHAPTER THREE

3.0 Results

A total of 154 out of 186 community volunteers providing Home Based Care in Mbeya Municipality participated in the study. The research team could not reach the other 32 during data collection period for various reasons. It was reported that some had either traveled out of the region and others had moved temporarily into their farms in the neighboring districts, as it was the harvesting season.

The Social demographic characteristic of the study population is presented in table 1. Female accounted for the majority of the community volunteers (68.8%) and males were (31.2%). The age distribution of the study population showed that nearly three quarters of the community volunteers were in the age groups of 30 – 49 while a fifth were between 20 – 29 years age group. The mean age was 36.7 years, standard deviation 7.94 and the range was 20-58 years. The majority of respondents had primary education 74.0%, followed by secondary education 20.1%. Adult literacy and those who had no formal education were less than 10%.

The distribution of study population by occupation showed that most of the community volunteers were small-scale farmers 43.5% and petty business people 40.3% while the employed people made up a small proportion of 16.2%.

Table 1: Social demographic characteristic of the study population (n=154)

Sex	Frequency	Percentage
Male	48	31.2
Female	106	68.8
Age (Years)		
20-29	30	19.5
30-39	66	42.9
40-49	48	31.2
50+.	10	6.5
Education		
No formal Educ.	5	3.2
Adult Education	4	2.6
Primary Education	144	74.0
Secondary Education	31	20.1
Occupation		
Employed	25	16.2
Petty business	62	40.3
Small scale farmer	67	43.5

3.1 Source of information on HBC

From the study it was found that there was no much difference as to the source of information among the four major sources of information most frequently mentioned. However, Non Government organizations and Mass Media were mentioned most frequently, 32.4% and 25.7% respectively (Table 2)

Table 2: Source of Information on HBC Services for the community volunteers (n=296)

Source of information	Frequency.	Percentages
Mass Media	76	25.7
Community health worker	50	16.9
Hospital worker	70	23.6
Non Gov. Organizations	96	32.4
Others	4	1.4

3.2 Experience of community volunteers in HBC services.

The majority (65%) of the community volunteers had worked in HBC for up to two years and only very few (16.2%) had an experience of 5 or more years (Table 3).

Table 3: Distribution of community volunteers by experience (n=154)

Experience in years	Frequency	Percentages
< 1	50	32.5
1-2	50	32.5
3-4	29	18.8
5+	25	16.2

3.3 Experience of HBC volunteer by sex

When the experience in HBC service was analyzed by sex, a statistically significant difference was found (Chi square 8.89, p = 0.02), with males staying longer in service than female (Table 4)

Table 4. Distribution of HBC by sex and experience in years (n=154)

	Experience in service in years				
SEX	**1**	**2**	**3**	**4**	**Total**
Male	12 (25.0%)	11 (22.9%)	13 (27.1%)	12 (25.0%)	48 (31.2%)
Female	38 (35.8%)	39 (36.8%)	16 (15.1%)	13 (12.3%)	106 (68.8%)
Total	50 (32 (5%)	50 (32.5%)	29 (18.8%)	25 (16.2%)	154

Chi square = 8.98, df = 3, p value = 0.02

3.4 HBC volunteer experience by the level of education and occupation

Variation of experience in service by the level of education, revealed differences that were not statistically significant among the different levels of education and non educated (Chi square 9.6, p= 0.14).

However, statistically significant difference was found when analysis of HBC experience by occupation was done, Community volunteers who were not employed stayed in HBC service for longer duration than those who are employed (Table 5).

Table 5: Distribution of HBC volunteers by occupation and experience (n=154)

	Experience in service in years				
Occupation.	1	2	3	4	**Total**
Employed	4 (16.0%)	18 (72.0%)	1 (4.0%)	2 (8.0%)	25 (16.2%)
Peasant farm.	21 (35.0%)	17 (28.3%)	13 (21.7%)	9 (15.0%)	60 (39.0%)
Petty bussin.	25 (36.2%)	15 (21.7%)	15 (21.7%)	1 4 (20.3%)	69 (44.8%)
Total	50 (32.5%)	50 (32.5%)	29 (18.8%)	25 (16.2%)	154

Chi square = 22.59, df = 6, p value = 0.0009

3.5 Problems encountered by community volunteers in providing HBC.

The respondents were asked on the problems encountered in the provision of HBC to HIV/AIDS patients. The most frequently mentioned problems were; no salary or allowance payment (20.4%), inadequate knowledge and skills on HBC (20.3%), inadequate supplies i.e. gloves, disinfectants, and gauze (18.9%) and lack of transport (17.8%) (Table 6). Variation of the constraints by socio demographic characteristics revealed differences that are not statistically significant.

Table 6: Distribution of Problems encountered by Community Volunteers while providing HBC (n=730)

Problems	Frequency.	Percentages
Inadequate drugs	73	10.0
Inadequate supplies	138	18.9
Lack of transport	130	17.8
Poor knowledge and skills	148	20.3
Lack of salaries and allowance	149	20.4
Poor community participation	67	9.2
Stigmatization	25	3.4
Total	730	100

3.6 Community Volunteers training.

The study found that majority (75.9%) of the community volunteers had attended some form of training in HBC, while 24.0% had not. However, when attending training was analyzed by sex and level of education the difference was not statistically significant.

When analysis was done to find out the relationship between attending training and the occupation of the community volunteer, a statistically significant difference was found, which shows the community volunteers who were employed had greater

chance of attending training related to HBC. The findings where statistically significant at p = 0.0005, as shown in table 7 below.

Table 7: Distribution of community volunteers by training and occupation (n=154)

	Training		
Occupation	**Yes**	**No**	**Total**
Employed	25 (100.0%)	0 (0.0%)	25 (16.2%)
Peasant farm.	37 (61.7%)	23 (38.3%)	60 (39.0%)
Petty .buss.	55 (79.7%)	14 (20.3%)	69 (44.8%)
Total	117 (76.0%)	37 (24.0%)	154

Chi square = 15.16, df = 2, p value = 0.0005

3.7 Type of Training (course) attended

Among those who attended training, it was found that 82.1% attended training on Home patient care and 13.7% received training on counseling very few respondents had reported training in prevention of HIV transmission (2.6%) and community mobilization and counseling on ARV drugs 0.9% each.

3.8 The duration of the course attended

When the respondents were asked about the duration of the course they attended, majority, (82.1%), of the Community Volunteers reported to have attended a two week course. Very few had either attended one week or four week course, 6.8% and

11.1% respectively. Regarding the adequacy of the course attended, majority of the respondents (95.7%) reported the course was not adequate

3.9 Additional training suggested by community Volunteers

All respondents, whether they had previously attended or not attended any training in HBC were asked to suggest what type of training they would prefer, most of the respondents mentioned training on treatment of opportunistic infections and counseling on ARV drugs 85.1% each, followed by Nutritional counseling 58.4% patient and family counseling 50.6% and patient care 37.6%

3.10 Support from other organizations

The majority of community Volunteers 97.4% reported that they received assistance from different organization

The most commonly reported assistances received from supporting organizations or individuals by Community Volunteers were; food assistance 30.9%, drugs supplies 22.3%, and patients counseling 21.9%, Table 8.

Table 8: Assistance provided by different organizations community Volunteers (n=310)

Type of assistance	Frequency	Percentages
Financial assistance	5	1.6
Drugs	69	22.3
Transport	9	2.9
Patient counseling	68	21.9
Food assistance	96	30.9
Spiritual support	52	16.7
Clothing	11	3.5

3.11 Organizations providing support to Community Volunteers

When the respondents were asked which organizations provided them with assistance, Non – Governmental and Religions organizations were more frequently reported 30.6% and 23.7% respectively, Table 9.

Table 9: Distribution of organizations providing support to the community volunteers n= 266

Organization	Frequency	Percentages
NGOs	97	36.5
Religious organizations	63	23.7
Individuals	60	22.6
Local government	34	12.0
Patient relative	12	4.5

3.12 Adequacy of organizational support to community volunteers

Majority (92%) of the respondents reported support they received from different organizations was not adequate.

When they were asked what more assistance was needed from the supporting organizations, the most frequently suggested assistance was transport assistance (25.0%), training support and salaries/allowances (24.7%) each.

3.13 Frequency of clients visits by Community Volunteers.

When respondents were asked about how often they visited their clients, majority of them, (88.9%) reported to visit their clients as frequently as demanded by the clients condition and needs.

3.14 Services provided by community Volunteers.

Regarding HBC services provided by community volunteers, Home patient care and Nutritional counseling were most frequently reported (38.6%) and (25.4%) respectively. (Table 10)

Table 10: Distribution of HBC services provided by Community Volunteer, n=295.

Service type	No.	Percentages
Patient care	114	38.6
Patient counseling	55	18.6
Spiritual support	38	12.9
Treatment of wounds	13	4.4
Nutritional counseling	75	25.4

3.15 Regarding assistance received from nearby Health facility

All respondents reported to get some support from the nearby health facilities However, when they were asked about the type of support they got from the health facilities, the most frequently reported assistance was patient treatment 96.8%. Other reported support provided by health facilities included patient counseling 33.8%, provision of supplies i.e. gloves, disinfectants etc 19.5% and provision of ARV drugs On the adequacy of Health facility support, most respondents, 83.1%, reported that the support was not adequate and only 16.9% reported support as adequate.

3.16 Additional health facility support suggested by community Volunteers.

The most frequently reported additional assistance or support needed from the health facilities were provision of supplies i.e. gloves and disinfectants (34.3%), availability of sufficient drugs at the health facilities (33.2%) and providing transport to patients visiting health facilities (26.3%).

Respondents were also asked whether they were paid for the services they provide and who paid then. All respondents reported that they were not paid anything and therefore the subsequent question was not answered.

CHAPTER FOUR

4.0 Discussion

4.1 Socio demographic information

Majority of the community volunteers providing HBC services in Mbeya Municipality are women. The finding supports findings from other studies that the HIV\AIDS issue has a gender perspective. It has also been reported that Community volunteers who provide HBC are mainly women and unpaid, (Cullinan, 2000). Women are highly vulnerable to HIV\AIDS, due to their biological and social cultural factors such as lack of self-determination in sexual maters. It is within the African culture that women are the traditional family carers who also look after the sick in the family. Women, who are also less exposed to the health information, bear most of the burden of the HIV\ AIDS pandemic. It is therefore important when planning HBC, using community volunteers, to take into consideration the need to empower women.

This study has also revealed that the majority of the community volunteers were primary school leavers. This could probably be due to the fact that most of the people in this group have no formal employment and they find it worthwhile to volunteer to help the sick in the hope that they may one day be employed, and get some payment. The government and all organizations involved in providing HBC need to take this scenario as a means to establish sustainable human resource base for HBC services by providing adequate training for this potential manpower.

Regarding occupation of the community volunteers, the study has shown that the majority of the community volunteers are not formally employed. Employed people are in most cases preoccupied with their employment responsibilities, as much as they would like to help the sick. Employment is also associated with transfers from one place to another, making it difficult to volunteer in providing HBC. With the unemployed this may again be seen as an opportunity with future expectation for an employment.

4.2 Problems encountered by community volunteers.

The findings of this study have demonstrated many problems that community volunteers providing HBC to HIVV/AIDS patients have to bear with. While the role of HBC organizations in the care of PLWHA is acknowledged, these organizations are by no means without challenges. Resources are scarce, even among well-established organizations like the Faith Based organizations.

4.2.1 Lack of salaries

Majority of community volunteers, reported lack of salaries as a problem in delivering home based care services to their patients, as in addition to attending to the patients, they have to struggle to get their individual and family needs. Many of care providers are not employed, they are either petty business people or small-scale farmers. Even supporting organizations like NGOs, Religious groups do not provide sufficient financial assistance for the volunteers to meet the needs of their clients.

Many HBC initiatives were started by church organizations or concerned individuals. Due to growing needs their services have always expanded beyond their capabilities, (Cullinan, 2000). The consequence for not paying salaries to community volunteers will be seen in excessive dropout of service, of previously trained volunteers, therefore making the HBC services even more expensive, as the need for training increases. The government needs to support the young HBC providers financially to make the services sustainable.

4.2.2 Poor skills and knowledge on HBC

Many respondents (96.1%) reported poor skills and knowledge as one of the encountered problems when dealing with HIV/AIDS patients. Although 75.9% of community volunteers reported to have attended short training on HBC, many see the course as inadequate for HBC services.

The study has also revealed that among those who attended training 82.1% received training on patient care and only 13.7% attended patient counseling. Regarding the duration of training, majority of the respondents, 82.1%, reported to have attended a two weeks training, and only 11.1% attended a four weeks training.

The problem of poor skills and knowledge among community volunteers may be a result of inadequate trainings provided by most organizations, which in turn may be attributed by poor financial position of the supporting organizations.

The HIV\AIDS disease is a chronic disease that goes through several phases which requires medical, psychological, social and economical, spiritual and legal care for both the patient and the members of the family. HBC provider should be trained sufficiently to identify the particular needs of the client at any particular time.

Volunteers need proper training because they are responsible for training family members for terminally ill patients, so they need to be well prepared to deal with wide range of medical and psychological issues. Some organizations are now providing up to six months training to its members. (Cullinan, 2000).

4.2.3 Inadequate Supplies

The study has shown that most community volunteers do not get enough working supplies. The most frequently offered assistance by supporting organization is food and drugs for the management of symptomatic manifestations even though not in adequate quantities as demonstrated in the respondent suggestions for improvements.

HBC provider needs to have sufficient supplies to attend HIV\AIDS patients to meet the needs of the patient and also to protect himself and other people from being infected. Inadequate supplies like gloves, disinfectants, gauze is a cause for discouragement and not providing care when needed leading to poor quality of service. The main reason for inadequate supplies in most cases is inability of the HBC providing organizations to cope with an increasing demand for services.

4.2.4 Transport

This study has shown that respondents are not provided with transport facilities. This is a serious set back in the delivery of home based care considering that, community volunteers have to struggle with their daily undertakings to make the ends meet and put aside time to provide care to HIV/AIDS patients. Many of them have to walk long distances to reach their clients, they get tired and de-motivated. Sometimes as a result of getting tired from their routine activities they just do not visit their clients hence compromising the quality of care. Transport is not only required by HBC provider to reach their clients, but is also needed to take seriously ill patients to the health facilities for treatment.

4.2.5 Poor community participation and stigma.

A community has a variety of roles and responsibility in the provision to HBC services. Effective implementation of HBC activities rest on the communities understanding that chronic illness among community members is not a problem of one individual but rather a problem of the whole community (NACP, 2005).

However, poor community participation and stigma has been reported in this study. People equate AIDS with death, and naturally people fear death. Poor community participation in HBC has a negative impact upon the quality of care provided by community volunteers, in that it reduces resources mobilization from within the communities, it weakens the spirit of volunteerism and discourages potential

volunteers to join HBC services. For those volunteers already in HBC, poor community participation in HBC weakens their desire to help the sick, makes them feel isolated and this may lead to low quality of care.

A study in Bagamoyo, on community participation in home based care, reported fear of contracting the disease as the main reason the poor community participation in providing HBC services to HIV\AIDS patients. (Msumi, et al., 2002).

In this study, stigma has also been reported as one of the challenges that the community volunteers have to bear with. Stigma also contributes to the poor community participation in HBC services. People feel that working closely with HIV/AIDS care providers would lead them to be labeled or even discriminated in the society.

4.3 Identifying training needs

Although majority of the Volunteers have attended short training on HBC, most of them reported the training as inadequate to meet the needs of the HIV/AIDS patients. Inadequate training may demoralize HBC providers, as the challenges for attending AIDS patients are many and very serious. HBC volunteers need to be trained in wide range of psychosocial, medical, legal, counseling and nutritional issues to provide quality services to their patients and the families. Various courses have been suggested by community volunteers, however, the majority (85.1%) have suggested

course on treating opportunistic infections and patient counseling on the use of ARV drugs, followed by nutritional counseling 58.4% and patient counseling. However, as the situation stands now, it may not be possible to immediately provide these trainings. Most support agencies lack funds and are unable to access funds from the government. Faith based organizations in resources scarce countries are unable to raise adequate funding on their own. Many NGOs were started with a hope that they would access funding from the government or foreign funding agencies, a dream, which has not always become a reality for various reasons. Experience has shown that it has always been difficult to access government resources. This is because resources are also scarce within the government and also due to complicated accounting system required by bureaucracy which are more often too difficult to be met by voluntary run organizations.

To meet the training needs, the government in collaboration with the organizations providing HBC should invest in the types of courses that will address adequately the needs of the community volunteers who will be able to meet the challenges of HBC for HIV/AIDS patients and their families. With the coming of ARV drugs many patients are enrolling for treatment. Their numbers will soon be too big for the current levels of existing human resource for health in the country. The HBC services through the community volunteers will bridge the gaps, therefore they need to be sufficiently trained.

4.4 Organizations providing HBC and services provided

The study has revealed that NGOs and Religious organizations provide most of the HBC in Mbeya 62.9% and 40.9% of the respondents draw their support from NGOs and Faith based organizations respectively. This finding supports findings from other studies. It has been reported that many HBC initiatives were started by Religious organizations and concerned individuals who were able to form organizations (Cullinan 2000). The roles of organizations providing HBC through community volunteers have been acknowledged in many parts of the world. Study conducted in Congo on whether community volunteers could deliver HBC found the recipients of the HBC benefited a lot from services offered by the volunteers, and volunteers were highly respected (Stredwick, 2003).

However, most of HBC organizations have financial limitations and therefore depend mainly on government funding and foreign financial agencies. Experience has shown that accessing money or any other resources from the government has not been easy, especially in poor countries, because of the scarcity of the same within the government itself and also due difficult accounting procedures which many voluntary organizations find it difficult to meet.

4.5 HBC services provided by community volunteers

As noted in chapter three, most commonly provided services by community volunteers are home patient care and nutritional counseling 74.0% and 48.7%

respectively. These findings may reflect the fact that most HBC volunteers are not well-trained offer a variety of services. Services provided mainly address the physical needs of the patients.

There is therefore a need to widen scope for the training for HBC providers to encompass other areas of the HIV/ADS patients' needs, which includes psychological, social and legal aspects. This will however require longer training sessions and more investment in terms of financial resources.

4.6 Health Facility Support

Regarding health facility support, this study has revealed that patients are taken to the health facilities when needed. This indicates that referral system exists and community volunteers use it. However, inadequacies in terms of patients needs have been reported. Inconsistence in drug availability, inadequate supplies, and lack of transport to take seriously ill patients to the health facility are most frequently reported deficiencies, which undermine the morale of the care providers and the quality of the care.

This finding indicates that most of the health facilities are ill equipped to meet the needs of the HIV/AIDS patients, and hence need for the planners to review the resource allocation in the health sector especially considering increased demand due to HIV/AIDS patients.

CHAPTER FIVE

5.0 Conclusions and Recommendations

5.1 Conclusions

This study has identified some gaps in the HBC provided to HIV/AIDS patients by community volunteers in Mbeya Municipality. These include:-

1. The majority of community volunteers providing HBC to HIV/AIDS patients are women, most of then have only attained primary education not employed and are not paid for HBC services they are providing
2. NGOs, Religious organizations and individuals support the majority of community volunteers.
3. Assistance provided by the supporting organizations is inadequate to meet the needs of the HIV/AIDS patients
4. The training attended by community volunteers was found to be inadequate to address the wide range of the HIV/AIDS patients and their families.
5. Poor community participation and stigma are some of the challenges encountered by that community volunteers

5.2 Recommendations

From the findings of this study the following recommendations can be made.

1. In order to improve on the quality of the HBC provided by the community volunteers to HIV/AIDS patients, the government and the organizations providing HBC to HIVAIDS patients need to sit together and workout how best to support community volunteers. This would involve making resources more available to meet the needs of the patients.

2. Increased community involvement and participation on HBC services is needed. This can be achieved through stronger community sensitization to make the communities understand its role in HBC. Communities should be made to own and therefore contribute resources to make HBC sustainable.

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