HOME BASED CARE SERVICES AS A STRATEGY TO SUPPORT ANTI-RETROVIRAL THERAPY ADHERENCE: THE CASE OF MUSOMA MUNICIPAL, MARA REGION

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Home Based Care Services as Strategy to support Anti-Retroviral Adherence: The case of Musoma Municipal, Mara region

By

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CERTIFICATION

The undersigned certify that she has read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a dissertation entitled: **Home Based Care Services as a Strategy to support Antiretroviral adherence in Musoma Municipal, Mara region** in partial fulfillment of the requirements for the degree of Master of Public Health of Muhimbili University of Health and Allied Sciences.

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Date_____

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I, Pamela Kokusima Rwezaura, declare that this dissertation is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree award.

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DEDICATION

This work is dedicated to parents Mr Bonny Bennedict Rwezaura and Mrs Juliet Lovin Bukagile.

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ABSTRACT

A descriptive qualitative study was conducted to assess whether Home Based Care services can be used as a strategy to support Anti-retroviral adherence for People living with HIV/AIDS (PLWHA) in Musoma Municipality, Mara region in March 2012. Six public health facilities that are providing ARVs were included in the study; this included the regional hospital, two dispensaries and three health centers. With the national ART scale up, the poor health infrastructures are faced with poor retention of patients into care, as a result maintaining adherence becomes a problem due to a lack of follow up. The goal of the study was to assess the use of home based care services as a strategy to support Anti-retroviral treatment adherence among PLWHA.

A total of five Focused Group Discussions (FGDs) were conducted with 30 home based care providers to find out from them whether the HBC intervention had experienced any changes since the advent of ARV scale up in the region, and whether their roles had changed in the delivery of services to PLWHA to include adherence support and management. Key Informant Interviews were conducted with 13 health care providers including the facility in-charges, CTC in-charges, hospital pharmacist and HBC Supervisor from the six health facilities that were included in the study to find out their perceptions towards home based care services and whether HBC is providing support to the formal health care systems in ensuring clients adhere to their ART regimen. Whereas in-depth interviews were conducted with 14 PLWHA who are taking ARTs to find out their perceptions towards home based care services and whether they support them with ART adherence.

The study findings revealed that HBC services support the formal health care systems with community care support services such as patient tracking and monitoring clients' adherence to ARTs. Health care providers revealed that the success of ART up in the region is faced with many obstacles including the poor rates of patient retention due to high rates of patients who miss appointments and those who default on their treatments. They revealed that this obstacle is being tackled by HBC providers who assist them to do the patient tracking and returning defaulters back into care, also they provide community supportive services including ART adherence and patient follow up. PLWHA who were interviewed attributed their good

adherence to the contribution of community support programmes such as HBC. They acknowledged the regular follow up visits, provision of counseling and monitoring that HBC providers conducted has helped them to maintain good adherence. This is because HBC has evolved in response to the roll-out of ARVs, where it has become more medicalised as a result of the drive to sustain PLWHA on ART to adhere to their treatment regimen.

It was concluded that HBC services are a key attribute that provides can be used to provide facility-community linkage which will ensure patients receive community care services as well as facility care and at the same time bridging the gap between formal health services and community care. Therefore further studies should be done on adherence interventions in order to develop evidence based strategies that can promote sustained adherence. In order for the national scale up efforts of ARV to be successful, it is important to assess the component of adherence as a contributing factor in ensuring the effectiveness or ARVs in achieving the desired results.

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AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ARV	Anti-Retroviral
CHBC	Community Home Based Care
CTC	Care and Treatment Center
DANIDA	Danish Development Agency
FBO	Faith Based Organization
HIV	Human Immunodeficiency Virus
HBC	Home Based Care
MoHSW	Ministry of Health and Social Welfare
NACP	National AIDS Control Programme
NGO	Non Governmental Organization
PLWHA	People Living with HIV/AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

CHAPTER ONE

1.0 INTRODUCTION

1.1 Overview of HIV/AIDS and its impact on the health care systems

Human Immunodeficiency Virus (HIV) is a serious public health problem in Tanzania, second only to malaria, with an estimated prevalence of 5.7% among adults (THMIS, 2010). HIV has had a major impact on health, economic and social progress reducing life expectancy, deepening poverty, and contributing to and exacerbating food shortages (National AIDS Control Programme 2003). It is a major global public health problem with an estimated 33.2 million people living with the infection, with Sub-Saharan Africa being the world's most severely affected region. (UNAIDS and WHO, 2007). Around 1.2 million people aged 15 and above, or just over 5 percent of the adult population, are living with HIV in Tanzania (UNAIDS; 2010).The number of People Living with HIV/AIDS (PLWHAs) who require medical attention continues to increase steadily, due to related diseases and conditions needing treatment and follow up. According to the World Health Organization (WHO, 2008), the antiretroviral therapy (ART) coverage was 44% in Sub-Saharan Africa by the end of 2008. In Tanzania, the estimated adult HIV prevalence was 5.7% in 2009 (equivalent to 1.4 million people), whereas a total of 96,000 people died of AIDS in 2008.

Public health care facilities are overburdened, and it is becoming increasingly difficult for them to provide quality care for the increasing demand. The HIV/AIDS pandemic has greatly increased the demand for health care, with reports from urban hospitals in Tanzania showing that patients with AIDS occupy approximately 50-60% of hospital beds. The impact of HIV/AIDS on the health care system has increased the need for treatment and altered the type of care needed for hospitalized patients.

1.2 Overview of Home Based Care Services

HBC Programmes for PLWHA started as early as 1987, although HBC services have been in existence long before then. HBC draws on strengths of families and communities, through provision of good quality and appropriate home care. This is something that was being done way before it was even formalized through a national policy framework. By 2002, WHO developed a framework for action on HBC in resource limited settings (WHO, 2002). This

was borne out of the realization that most of the HBC services had been established through unsystematic and needs-based efforts. HBC is considered as one of the answers to the health care systems failure in resource limited settings to respond to the health needs as well as the general population, whereas it can be classified into preventative, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories. Provision of HBC has been one of the most effective community care strategies in developing countries for PLWHA, this is because the poorly equipped and highly understaffed public health care systems are failing to cope with the extra demand of caring for the AIDS patients (in and out of hospital).

1.2.1 Development of Home-Based Care Services in Tanzania

Due to the increasing numbers of patients who were bedridden, the need for HBC increased and many national and international organizations started related activities, mostly targeting PLWHA only. Since the scope of HBC services was not clearly defined, patients with HIV/AIDS were discharged from hospitals without any proper referral system for ensuring a continuum of care. Thus there was a need to train HBC providers who would be responsible for training and supporting the patient's families, who would in turn continue taking care of these patients in the homes. The goal is to provide hope through good quality and appropriate care that helps patients and families maintain their livelihoods and the best possible quality of life. Also various studies have been conducted which confirm that people would rather be cared for at home, and that effective home care improved the quality of life of those who are sick. (Lindsey, 2002).

Implementation of organized HBC services by the Ministry of Health and Social Welfare (MoHSW) in Tanzania started in 1996 as pilot projects in eight districts of the Rukwa and Coast regions with support from Danish International Development Assistance (DANIDA). Findings from the pilots revealed that the services were highly appreciated and in ever increasing demand. Since then many organizations, including WHO and UNAIDS, international and local NGOs, Faith Based Organizations (FBOs), and community groups, have joined in to support HBC services in different parts of the country. By 2002, HBC services had been established in 28 districts, and by the end of 2006, the services had reached 70 out of 126 districts, with an estimated 50,000 patients reached (Van Praag *et al,* 2007)**.**

HBC has emerged as an effective method of providing cost-effective, compassionate care to those infected and affected by HIV/AIDS, it is not a replacement for hospital care, but instead is part of a comprehensive continuum of care that is provided through the community by involving community members in prevention, care, and support efforts. In Tanzania HBC services follows two approaches: (1) health-care staff trained as HBC providers to deliver outreach services on a part-time basis in addition to performing other healthcare duties in hospitals or clinics, or (2) trained community-based providers who are primarily volunteers working for NGOs, FBOs, or CBOs providing HBC services exclusively. The latter approach is the approach most often used.

1.3 Anti-Retroviral Therapy Roll out and Adherence in Tanzania

Tanzania has made a good start in rolling out ARTs since October 2004 and by the end of 2006, the NACP within the MoHSW had already covered all 21 regions and 132 districts in Tanzania. Ensuring that PLWHA receive ART treatment has had an extraordinary impact on HIV related mortality, enabling people to lead relatively normal healthy lives. However the main challenge is poor adherence which is attributed by many factors including socio-economic, clinical and socially related factors. Unfortunately very few studies have paid attention to the component of adherence in the care and treatment of HIV/AIDS, whereas the national guidelines for care and treatment of HIV/AIDS do not have a tool to assess adherence. Unless due attention is paid to the issues of adherence, resistant to both first line and second line drugs will develop or be inevitable and this will reverse the expected early treatment achievements. The MoHSW through its national programmes needs to emphasize the importance of treatment adherence so as to ensure the effectiveness of current national efforts in the scale up of ART. As ART is being scaled up in Tanzania, there is a need to study the role that HBC programmes can play in order to ensure adherence to drugs especially among PLWHA in the communities.

1.4 PROBLEM STATEMENT

The devastating impact of HIV/AIDS in the world especially in sub-Saharan Africa has led to an unprecedented global effort to ensure access to ART medicines to treat the disease in every country where HIV is a threat. In Tanzania, the country embarked on the road to universal

access to ART in 2004 with focus on building systems that would ensure the roll-out of ART. This universal access did not focus on achieving client centered issues, hence did not look at any mechanisms of putting in place a social support package that would support clients to enroll onto ART and also to subsequently support them with adherence. Despite the increasing allocation of resources to expand access to ART in Tanzania, little is known about how best to deliver treatment services and in particular how to ensure adherence to the drugs. Since ART was introduced in Tanzania, there has been no mechanism to ensure that those who are initiated on ART are monitored to maintain good adherence rates. As a result of this, Tanzania's national response to HIV/AIDS is facing the threat of not achieving the desired results with the ART scale up. This necessitated efforts to shift from solely based on prevention to include more emphasis on care and treatment support for PLWHA and adherence management.

Whereas among the many bottlenecks that prevented effective ART adherence included the lack of follow up on PLWHA who are on ART to ensure adherence, this was largely attributed to the limited capacity of national health systems, including shortage of human resources to enforce follow up. Factors that are associated with failure of viral suppression and progression to AIDS or death for PLWHA include adverse drug reaction, and non-adherence to ART. The later increases the risk of viral mutations, which can result in cross-resistance to other medications or transmission of multi-resistant virus strains, and thus the risk for initial therapy failure in subsequently infected individuals. Social support structures are more important as efforts shift from an enrollment phase to a sustained phase, and adherence is imperative to guarantee the effectiveness of ART.

The administration of ART to individual patients and the monitoring and evaluation of HIV/AIDS treatment programmes critically depends on regular and complete patient follow up. Due to the increased demands resulting from the scaling up of ART, it is clear that the formal health care system alone cannot carry out all the steps necessary to get the large numbers of people to maintain treatment adherence successfully. As much as many health facilities are providing ARTs, there needs to be a system to ensure adherence, since this aspect is critical in any ART programme. The linkage between the patient and adherence support has

largely been lacking to holistically address adherence problems, as a result additional interventions are required to address the issues of adherence. HBC services provide a holistic approach by providing adherence interventions through continuous home visits, provision of education on adherence management, pill count adherence and reminders during clinic refill days. However, since the HBC strategy was introduced in Tanzania, there is little documentation on whether this strategy is indeed supporting adherence as initially planned.

1.5 RESEARCH QUESTIONS

1. What roles do HBC service providers play in supporting ART adherence among HIV infected persons?
2. What are the perceptions of health care providers towards Home Based Care services in facilitating ART adherence?
3. What are the perceptions of clients enrolled in ART services towards HBC services in supporting ART adherence?
4. What challenges do HBC providers face when rendering services to clients?

1.6 RATIONALE OF THE STUDY

As large-scale programmes to provide ART for HIV/AIDS have expanded and matured in Tanzania, there have been no studies focusing on whether these ART programmes are achieving the desired results. This is because there have been no attempts to investigate adherence as a contributing factor to ART scale up and target achievement. Thus there is a need for attention to be shifted from only focusing on treatment, access and initiation to the broader set of long term challenges in sustaining a vast and complicated public health endevour. Maintaining good adherence is very demanding for PLWHA and with the limited resources in the health sector, it is not always the case that PLWHA get the support they need from the health care system structures. Whereas it has become increasingly clear that as access to ART becomes available, it improves the lives of PLWHA, these efforts need to go hand in hand with strategies for supporting adherence. This is due to the fact that PLWHA face a lot of problems in trying to adhere to their treatment regimen including a lack of psychosocial support to enforce self management. In Tanzania, there have not been any studies that have

looked at ART adherence in the community, despite the fact that health facility records are showing huge numbers of patients who are Loss to follow up (LTFU).

Since HBC services are already in existence in our communities, they can be used to provide the complimentary support needed to ensure ART adherence among patients. Furthermore the study explored various contexts of delivering HBC services and documented the additional or changing era of HIV/AIDS which may contribute to ensuring and maintaining adherence. Maintaining adherence would impact strongly on achieving the target of scaling up ART to all PLWHA and ensuring the desired outcome is achieved. The findings of the study can therefore be used to re-think the position of HBC as a programatic response to the weak public health infrastructures in the era of ART.

1.7 OBJECTIVES

1.7.1 Broad Objective

To assess the use of Home Based Care services as a strategy to support Anti-retroviral treatment adherence among PLWHA in Musoma Municipal.

1.7.2 Specific objectives of the research were:

1. To explore the role of home-based care service providers in supporting ART adherence
2. To determine the perceptions of health care providers towards Home Based care services
3. To determine the perceptions of clients enrolled on ART towards Home Based Care services
4. To describe challenges faced by HBC providers in rendering services to their clients.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Overview of Adherence to Anti-Retroviral Treatment (ART)

The concept of 'adherence' has a broader meaning than compliance. It encompasses the extent to which a patient follows instructions and implies understanding, consent and partnership. It also includes entering into and continuing in a programme or care plan, as well as keeping appointments and tests as scheduled. This largely depends on the individual's frame of mind as well as the support of family members, the people around them, and the community at large. Administration of ARTs imposes constraints on the daily schedule and lifestyle and it can be difficult for individuals to adapt to these demands, especially on a long term basis. Patient adherence to ARTs is an issue that is growing in prominence and generating a burgeoning interest with their roll-out. In the absence of a cure, ART is the only available option that offers the possibility of dramatically reducing HIV/AIDS-related morbidity and mortality, while improving the status of PLWHAs. However, successful administration of this treatment depends on sustained and strict adherence to the prescribed regimens.. Lack of ART adherence can lead to treatment failure, disease progression and emergence of drug resistant HIV/AIDS strains (Poppa *et al,* 2006).

According to WHO, understanding the need for complete adherence is the cornerstone of successful ART treatment for every patient. Lack of adherence to ART is one of the main causes for failure of the treatment worldwide and one of the main concerns when providing these drugs especially in developing countries. Resistance to ART is becoming an increasingly problematic issue and the effectiveness is compromised due to lack of effective care and support. Without regulated treatment adherence, rapid emergence of drug resistant viral strains and individual treatment failure is a potential threat that could curtail treatment options. Adherence interventions are needed for durable effect, particularly in chronic diseases such as HIV (Sharon et al 2006). In order to increase adherence to ART, there needs to be concerted efforts to ensure continuous monitoring through ART adherence support and follow up. Research suggests that after being on ARTs for a while, patients can expect an undetectable viral load if they are good adherers. As evidenced by a citation of the Ministry of Health

(2003) in Uganda, 78% of patients were found to have an undetectable viral load within six months, with more than 95% adherence.

The introduction of ARTs in the 1990s brought new hope to PLWHA by changing the way people view HIV. Despite the fact that they do not provide a cure and pose additional challenges due to potential side effects and the emergence of drug resistant strains of HIV, they have dramatically improved rates of mortality and morbidity, improved quality of life, revitalized communities and transformed the perception of AIDS from that of a plague to a manageable, chronic illness (UNAIDS, 2004). More recently, the increased availability of treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections in PLWHAs (UNAIDS, 2005). Those who have access to ARTs and the care needed to maintain therapy can live for many years with what is now considered to be a complicated but manageable chronic disease.

Nevertheless, concerns have been raised about adherence to ART and its possible consequences, the most serious one being the acquisition of viral resistance that can threaten the effectiveness of treatment and its long-term benefits for HIV-infected individuals. Previous studies have already highlighted a number of similar determinants of adherence to ART in low, medium and high-income countries, such as perceived side-effects or depression. However, if one takes into account the cultural and economic contexts, then a greater number of determinants may influence adherence to ART in HIV-infected individuals. For instance, it is known that for patients living in poor settings, they face financial and geographical difficulties in accessing treatment which can impair their adherence. In addition, adherence is a dynamic process which changes over time and cannot be reliably predicted by a few time-varying patient characteristics. That is why access to ART needs to be accompanied by adapted methods of helping patients adhere to their treatments.

A growing body of literature from developed countries has underscored the importance of adherence for the successful administration of ART and WHO has identified adherence as the most important issue in the scale up of ART programmes. The implication of adherence requires that one takes the medication in the right quantities and adheres to the dietary and

lifestyle changes (Garcia *et al,* 2003). Despite elevated adherence requirements, studies have shown that non-adherence to ART is widespread. For example, Rao *et al* (2000) reports that adherence rates for youths range from 27%- 41%. Similarly Chesney *et al* 2000 points out that as many as 10% of patients miss a dose a day and on aggregate non-adherence to ART is estimated at between 50-80% in different social and cultural settings (Amico *et al* 2003). At the public level, non adherence to treatment may cause the development of multi drug resistant strains leading to dire public health implications. Adherence is therefore central to the success of ART programmes, and to reiterate the significance of adherence, Lewis *et al* (2006) observes that a non-adherent patient is 3.8 times more likely to die than an adherent one who follows the same treatment.

2.2Antiretroviral Treatment and Adherence in Sub-Saharan Africa

A study conducted in 2007 by the Foundation for AIDS Research observed that only slightly more than 60% of patients enrolled in ART programmes in sub-Saharan Africa continued treatment two years after initiation. In addition, 40% of patients who stopped ART died within two years. This study, which collected data from 13 sub-Saharan African countries, provides insights into programme initiation and adherence rates. It also raises concerns regarding future policies, programme implementation, and resource allocation for ART protocols in resource poor settings. Scaling up and ensuring the availability of ART is crucial for reducing mortality and HIV transmission (Lucas *2002*). ART offers an opportunity to prolong lives of PLWHAs and revive societies that have been affected by the epidemic. While access to ART is vital, it is equally important to ensure that patients adhere to the prescribed regimen. Suboptimal adherence to ART increases the risk of drug resistance development amidst the limited options for second-line treatment in resource poor settings (Bangsberg *et al,* 2005). Therefore, monitoring the patients' adherence to ART is a requirement for adequate HIV care provision, while researching and understanding the factors influencing adherence can lead to development of effective interventions.

During the last decade, access to HIV care in Sub-Saharan Africa has been improved by reduction in the cost of ART and by the implementation of WHO guidelines promoting

scaling-up by task shifting for clinical decision-making to less specialised health-care workers (Gilks e*t al*, 2006). However, the challenge to achieve high adherence to ART is particularly acute in Sub-Saharan Africa as the high rates of HIV/AIDS lead to greater absolute numbers of affected individuals than in other low-income regions. Although long-term good ART adherence has been observed in certain settings of public sectors in Africa, the magnitude of this challenge in Sub-Saharan Africa remains large (Brinkhof, 2008; Rosen *et al*, 2007) and there is growing evidence for high rates of patient's lost to follow-up.

Although adherence to treatment is a crucial aspect of ART programmes, there is a paucity of studies on ART adherence in resource poor settings such as Sub- Saharan Africa (Byakika *et al*, 2005, Paterson *et al.*, 2000). Thus the expected patient adherence rates commonly used are derived from studies performed in resource-rich countries. This could be due in part to the fact that much of the effort in the South has been devoted to providing access to those in need, rather than concerted efforts to study adherence rates. Moreover, given recent roll-out initiatives, the challenge is changing from gaining access to ART, to maintaining the required adherence in order to realize the full benefits of reduced HIV- related mortality and morbidity, as well as improved quality of life (Sarna *et al*, 2005). The results of previous studies that have been done in Tanzania, on other diseases have indicated that patients often do not have enough knowledge and/or do not remember how to use various prescribed medicines, contributing to their irrational use. This has also been observed in many other settings where ARTs are used. For example, in a previous study in Botswana, 54% of patients reported optimal adherence (defined as completing greater than or equal to 95% of prescribed doses) and 56% were seen as achieving optimal adherence on the basis of provider assessment (Weiser *et al*, 2003). The main factors affecting ART use in Botswana were structural, disease related and treatment-related factors, and socioeconomic and cultural factors. For instance, patients lacked funds and had to travel long distances to the clinics providing ARTs.

2.3 Socio-demographic Characteristics and Anti-Retroviral Treatment Adherence

The role of socio-demographic characteristics, such as gender, race, age, exposure category and educational level as predictors of adherence has produced largely inconsistent results

according to studies that have been conducted. The tendency to ascribe low adherence to (often deprived) social groups is a well established trend in the general literature, dating back to 1990 when tuberculosis control occupied public health officials. However, as later experience with antibiotics demonstrated, low adherence is not restricted to certain social classes but is widespread and unpredictable. Research in the HIV field supports this perspective. Moreover adherence rates vary not just between individuals but also for the same individual over time. Adherence is therefore best thought of as a variable behaviour rather than as a constant characteristic of an individual. Beliefs about health and illness, in particular about the necessity of medication to ward off illness and concerns about potential adverse events, have been found to be influential in both HIV and other disease areas.

2.4 Linkage of Home Based Care and Adherence

Adherence to ART among patients living with HIV/AIDS is critical in any ART programme. Much as most health facilities have established measures to ensure increased coverage for ART, there are no sustainable systems to routinely follow up patients on ART and address issues that impact negatively on adherence. As the use of these drugs becomes a reality in developing countries, adherence to the treatment regimen also becomes a bigger issue that needs to be addressed in these settings. The renewed focus of HBC as a strategy for providing HIV care in the context of ART provision has led to calls for evidence of its effectiveness (Jaffar et al, 2005; Korenromp and Kayondo, 2008), and several epidemiological studies have recently been undertaken to investigate its impact on a variety of outcomes. Nonetheless, the challenges in the region remain great as health systems are weak, and the target orientation of ART programmes risks an emphasis on initiating people on treatment at the expense of ensuring effective use of these medicines. Extremely high levels of adherence (at least 95%) are needed to ensure positive treatment outcomes to prevent the development of drug resistance (Paterson et al 2000). HBC providers have increasingly linked their services to the public health care systems, whereas before, HBC services tended to operate in relative isolation with limited referral to and from the health facility. There is now more cooperation between the different actors in the continuum of care with the services being integrated in national HIV policies. There is also realization that treatment adherence to ART needs to

extend to the community, acknowledging the importance of linking the HBC service providers with the national health systems. For persons with chronic illnesses such as AIDS, a well functioning HBC programme provides a continuum of care that extends from the health facility to the home settings.

To be effective, HBC programmes need to be integrated into the existing district health care delivery systems and plans. Any scale-up of HBC programmes that incorporates ART delivery or care for patients on ART will require collaboration between different stakeholders involved in health service provision. As their name suggests, the effectiveness of any comprehensive programme depends partly on their ability to create well functioning linkages between health facilities and organizations providing a range of care, treatment, prevention and support services. Scale up of ART in resource-limited settings should consider not only the number of new patients starting ART but also the numbers remaining in long term care; the numbers lost due to lack of follow up is an important indicator of programme effectiveness. Despite this linkage and the presence of national HBC policies or guidelines, governments in many African countries continue to regard HBC as an intervention that is to be delivered by NGOs, FBOs with limited domestic resources allocated to HBC services.

The need for greater emphasis on strengthening linkages and referral mechanisms in order to create effective local contexts for providing HBC has been extensively reviewed by Campbell and Foulis (2004), who noted that there has been a lack of systematic research into the types of linkages and partnerships that can promote effective exchanges between those involved in supporting HBC initiatives in the context of ART scale up. Available information suggests that although many countries are scaling up ART a programme, no one has developed any practical approaches to monitor how well patients adhere to their treatment. A central dimension of the challenge involves the health systems through which services are delivered but there is a lack of mechanisms in place to ensure adherence. This is crippled with the overwhelming work load in congested HIV care clinics, combined with the low numbers of health care providers which as a result hinders any efforts of conducting patient follow up and monitoring ART adherence. Thus there is a need for documenting and strengthening the

linkage between HBC and other services, including strengthening the linkage between clinical services and community based care so as to ensure continuum of care.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study Design

The study used a qualitative descriptive design, whereas this design was employed in order to promote quality of the process of obtaining data from participants in order to produce the required results. Burns and Grove (2007) postulate that descriptive research is aimed at describing and exploring research phenomenon in real life situations.

3.2 Study area

The study was conducted in Musoma Municipal, which is one of the six districts of Mara region in Tanzania. Mara region is bordered by Mwanza and Shinyanga regions to the south, Arusha region to the south east and Kagera region through Lake Victoria. According to the 2002 Tanzania National Population Census, the population of Mara region is 1, 368,602. This region is among the five regions of Tanzania with high HIV infection, with a prevalence rate of 7.7% which is above the national rate of 5.7% (THMIS 2007/08, TBS, 2008). Apart from Musoma Municipal, other districts in this region include Musoma Rural, Tarime, Rorya, Bunda and Serengeti.. The distribution of health facilities in Musoma Municipal includes 23 dispensaries out of which seven are government and 16 private. CTC services are provided in two of the government dispensaries while they are available in only one private dispensary. The three health centers in the district are all public and all of them provide CTC services. The regional hospital is located in this Municipal and it provides CTC services.

Mara region was selected for this study because there are already existing HBC programmes in addition to having a high prevalence of HIV. Musoma Municipal was specifically selected as the district of focus because of its location and existence of different activities some of which pose a high risk to HIV infection. It is also the hub of commercial activities such as fishing, attracting an influx of people from the other districts who come in to do business.

3.3 Study populations

The study included 30 HBC providers giving continuum of care services to PLWHA, 16 patients who were taking ART and attending CTCs at the time of data collection and 13 health care providers in selected public health facilities in the Municipality.

3.3.1 Inclusion Criteria

Respondents who participated in the study were HBC providers who have been providing HBC services to HIV/AIDS patients for at least three years. This criterion was set to enable the respondents reflect well on the HBC intervention and put them in a better position to discuss their roles in delivering the services and the changing trends in view of scaling up ART in the region. Other inclusion criteria were consenting HIV positive clients aged 18 years and above who had been taking ARTs for at least three years and were enrolled in HBC programmes. The duration that someone had been taking ARTs was considered as this put them in a better position to discuss ART adherence issues.

3. 4 Sample Size and Sampling Procedure

A total of 16 In-depth interviews were conducted with PLWHA, whereas five Focus Group Discussions (FGDs) were conducted with HBC providers in selected health facilities as follows; Regional hospital (one), public health centers (two) and public dispensaries (two). A total of 13 key informant interviews were done as follows: at the regional hospital- CTC in-charge, pharmacist and HBC supervisor who is also an adherence counselor; while at the three public health centers similar interviews were done with the facility and CTC in-charges and at the two public dispensaries interviews were conducted with the facility and CTC in-charges as well as the HBC supervisors.

This study made use of purposive sampling as its sampling strategy. This type of sampling allows the judgment of the researcher to be used in the selection of the study respondents. Selection of clients for in-depth interviews was done at the CTCs with the assistance of the CTC in-charge and HBC supervisors at the health facilities that were selected for the study. Health care providers were purposely asked to assist in the selection process as they are the ones who deal with the clients on a daily basis, hence know the clients strengths and

weaknesses through their regular interactions with them. This selection process was used so as to ensure the participants that were selected for the in-depth interviews had rich information with regards to what the study wanted to find out and were open about their HIV statuses and therefore they were to ready to discuss different issues including HIV and ART uptake.

The selection of participants for the FGDs was done by HBC supervisors by calling the HBC providers and made arrangements with them. The HBC supervisors made use of the regularly scheduled clinic days at the health facilities to schedule the FGDs with the HBC providers, as this ensured that the HBC providers would come to the health facility, as it was routine for them to come to the health facilities on clinic days to render different services including ART adherence classes and also to receive any updates from the CTC in-charge if they were any clients who had defaulted and needed follow up. Key Informant Interviews were conducted with the facility in-charge, CTC in-charge, Pharmacist and HBC supervisors. These respondents were selected as they are in a better position to give an overview of the HBC services and provide information that is needed to meet the objective of the research, as they are the ones who deal with PLWHA who are enrolled in CTCs on a daily basis

3.5 Recruitment of Research Assistants and Training

One research assistant who was an HBC supervisor from the regional hospital was recuited to assist with the data collection. Factors that were considered in the recruitment were previous experience in working with PLWHAs, experience in HBC services, experience in collecting qualitative data and good communication skills. The research assistant was oriented on the study objectives, overview of data collection processes, obtaining consent of the participants, interview skills, understanding the interview guides and the need to employ different use of the research tools including the use of the tape recorder when conducting discussions with participants.

3.5 Data Collection Techniques/Instruments

Three data collection techniques were used in this study and they included FGDs, In-depth and Key Informant Interviews using respective interview guides which allowed flexibility for probing. Qualitative researchers are allowed to make use of probes in order to deepen the

responses to the questions. According to Patton (1990), a probe is a follow up question used to go deeper into the interview responses.

The FGDs comprised of six respondents per group and each session had a note taker (the research assistant) and moderated by the Principal Investigator. Participants were informed of the use of the tape recorder and also note taking of the discussions. In some of the FGDs the participants were not comfortable to be tape recorded; hence only note taking was done during the discussions. In-depth and key informant interviews used guides also to facilitate discussions. The guiding questions were initially written in English and then translated into Kiswahili which is medium of communication that was used during the study.

3.7 Data Management

Data was collected on a daily basis from the respective facilities according to plan, ensuring that all the themes were exhausted. A thematic analysis of all the information collected was conducted to identify, analyse and report patterns, which were condensed into units of analysis. These units were labeled and categorized into sub-categories. The grouped categories formed the framework for analysis, whereby the words, phrases or events that appeared to be similar were grouped into the same category. During subsequent stages of analysis the categories were used to organize the raw data, so as to bring meaning. This organized data was modified into summaries and presented as results of the findings of the research. Field notes that were gathered from the in-depth interviews and the information from the Focused Group Discussions were also used to supplement the information collected by the note taker during the FGD sessions. Any additional information acquired through the tape recorder was also listened to, reviewed as additional information which was condensed into categories and units of analysis.

3.8 Ethical Considerations

Ethical clearance was obtained from the Ethical Committee of the Directorate of Research and Publication of Muhimbili University of Health and Allied Sciences (MUHAS). Permission to conduct the study was sought from the Regional and Municipal authorities in Mara region supported by the letter of introduction from MUHAS. Also a request from the health facilities

involved in the study was sought from the Health facility in-charge. The consent of the study subjects was sought from the research participants after explaining to them the objectives of the study. Issues of confidentiality were shared and the participants were assured of their voluntary participation in the study. Participants were also assured their responses will be kept confidential and their names will not appear in any of the documents.

CHAPTER 4

DATA ANALYSIS, PRESENTATION OF FINDINGS AND DISCUSSION

4.0 Introduction

This chapter presents data in relation to the four objectives of the study whereby the major issues included, describing the role of HBC providers in supporting ART adherence; determining the perceptions of health care providers as well as clients enrolled on ART towards HBC services and describing challenges faced by HBC providers in rendering services to their clients. Data was obtained from individual in-depth interviews with 16 clients on ARTs whereas five FGDs with groups comprising of six respondents each were conducted with HBC providers. Furthermore, 13 key informant interviews in the selected facilities were conducted with the facility in-charge, CTC in-charge, HBC supervisors and the pharmacist at the regional hospital.

4.1 Data Coding, Organization and Reduction

This was a qualitative study as defined by Cresswell (1994) and Denzin and Lincoln (1994) is an inquiry process of understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views of informants and conducted in a natural setting. It examines the patterns of meaning which emerge from the data and these are often presented in the participants own words. The major sources of data in qualitative research are audiotapes and field notes. In this study therefore, some of the unstructured interviews were recorded on audiotapes as well as through field notes in order to ensure that the narrative statements denoted the original and true meanings of the first speakers.

The data from each interview was read and key words/themes and significant statements were selected, reviewed and put together into different clusters. It was noted that different participants often used the same or similar words and phrases to express the same idea which helped to shed light on the research and these formed themes. Different clusters with similar themes were then grouped together for analysis. Key words (codes) were assigned and memos that explained the thinking about the data were written down. Text that was relevant and related to the specific research concerns was taken. The interviews were transcribed verbatim, a critical step in preparing for data analysis (Polit and Beck 2004). Although most of the

results are qualitative in nature, some areas of inquiry were enriched through blending of qualitative and quantitative data to enhance validity of the research findings (Polit and Hungler,1999). In this research therefore, descriptive statistics have been used in the presentation of demographic data in the form of tables.

4.2 Social Demographic characteristics of the study participants

Although they were not directly concerned with the purpose of the study, demographic information was, however, collected and analyzed to determine the characteristics of the different study respondents. The information gathered related to age, sex and occupational status and the analysis yielded the following results; among the 30 HBC providers who participated in the focus group discussions, half of them were between the ages of 25 and 34 years, whereas 8 and 5 participants (27% and 17% respectively) were between 35 and 44 years and two (6%) were aged over 55 years. The mean age of the participants was 28 years and 21 (70%) of them were females. On the other hand, half of the 16 HIV positive clients who participated in the study were between the ages of 25 and 34 years, whereas 6 (37%) of them were aged between 35 and 44 years with 11 (69%) of them being females. Among the 13 health care providers who responded as key informants, 9 (69%) were females.

As indicated on Table 1, it was important to document the various sources of income of the study respondents, especially for the HIV positive clients and the HBC providers. Three categories of potential income generating activities in the study area were included for the HBC providers whereas out of 30, 18 (60%) were in the fishing sector. For the 16 clients who on ART, 9 of them (56%) were engaged in small scale business and the remaining 7 were in the fishing sector. The health care providers represented four cadres of the health sector where 6 (46%) were nursing officers while 4 (31%) were clinical officers.

Table 1: Distribution of the study respondents according to occupational status:

	Frequency	Percentage
HBC Providers (n=30)		
Fishing	18	60
Small scale business	10	33
Employed	2	7
Clients who are on ARTs (n=16)		
Small scale business	9	56
Fishing	7	44
Health Care Providers (n=13)		
Nursing Officer	6	46
Clinical Officer	4	31
Assistant Medical Officer	2	15
Pharmacist	1	8

4.3 Qualitative Study Findings

The findings are presented in sections mirroring the study questions and objectives through the major themes that were identified from the data collected..Such analysis involves a process that is designed to condense raw data into categories/themes based on valid interpretations. The readability of the qualitative reports is usually enhanced by the inclusion of verbatim excerpts taken directly from the narrative data (Polit and Hungler, 1999). The table below highlights the identified themes with the supporting sub-themes that emerged during the analysis of the interviews.

Table 2: Identified themes related to HBC as a strategy to support ART adherence

Main Theme	Sub-Themes/Categories
The roles HBC service providers play in supporting ART adherence among clients enrolled in CTCs	1.1 Main tasks for HBC providers 1.2 HBC providers knowledge of ARTs 1.3 Overview of the changing roles of HBC providers since the introduction of ARTs 1.4 Integration of HBC into the formal health care system
2. Perceptions of health care providers towards HBC providers in facilitating ART adherence	2.1 Health care providers views about ART adherence 2.2 Perceptions on whether the HBC providers provide support in ART adherence
3. Perceptions of clients enrolled in ART services towards HBC services in supporting ART adherence	3.1 Client's knowledge of HBC services 3.2 Client's views about ART adherence 3.3 Client's perceptions towards HBC providers in supporting ART adherence 3.4 Overview of the changing roles of HBC providers since the introduction of ARTs
4. Challenges faced by HBC providers	4.1 Challenges faced in the provision of HBC services

Theme 1: Roles HBC service providers play in supporting ART adherence among clients enrolled in CTCs

For any country's health sector to be effective especially in the advent of ARTs, it needs to engage new strategies that will help to tackle the changes that have been brought about by the epidemic. This is because the HIV/AIDS epidemic has changed around the world after the advent of ARTs, but many health systems are failing to cope with the increasing numbers of people who are on ART that need care and support to remain on treatment. HBC supervisors from the six health facilities emphasized the important roles HBC providers play in assisting the health care providers with community support services. These include patient monitoring, following up and tracking defaulting clients. Health care providers further acknowledged the good return rates of clients as a key result of the follow up that is being done by HBC providers. This move was seen to positively impact on client's adherence to ARTs since they are constantly reminded that once initiated, they must be taken as advised. A good example that was shared by all the health care providers was the fact that in many instances they are required to do client monitoring in the community as opposed to just seeing patients at the

health facility. However, they admitted that their heavy workload and understaffing deter them from going out into the communities to make a close follow up to patients on ARTs. They therefore need the assistance of HBC providers to do the follow up in the communities to enable the tracking. This model of facility and community supportive care is being used at all the six health facilities that were involved in the study.

Similar observations have been highlighted in a study that was done in Zambia on Evidence of the importance of the roles that HBC providers play: Lay Workers vital roles to support ART roll-out (DFID, where it attributed their vital roles as ART treatment supporters to be very beneficial to PLWHA especially with the era of ART scale up in many countries. In another study that was done in Uganda, Home Based AIDS Care project demonstrated high levels of adherence to ART among a cohort of patients who received a range of care, prevention and support services at their homes. The project compared the social experiences of ART patients at baselines and after three months of receiving weekly HBC visits. The study revealed that 84% of the clients attributed their good adherence on their participation in the HBC programme.

In order to draw conclusions on the above theme, sub-themes that emerged during analysis of the data that support the main theme are discussed below:

Sub-Theme 1.1: Overview of the main tasks of HBC providers

Different researchers have attributed the introduction of HBC to a number of reasons including the preference of patients and their families who preferred to be cared for at home. Whereas provision of care in the home was seen by many as a cost effective strategy of having HBC providers visit them at their homes and provide them with the care they needed, but also the emergence of HBC was an effective method of providing cost effective compassionate care to those infected and affected by HIV/AIDS. It was not a replacement for hospital care but instead it was part of a comprehensive continuum of prevention, care, treatment and support services that include the family and community at large. Therefore it was important in this study to assess the HBC providers' knowledge of their tasks and what is expected of them as they render HBC services to clients.

When conducting FGD sessions, each HBC provider was encouraged share their views on what their main tasks were in rendering the services. All the responses were highlighted and the main tasks were grouped into clusters for further analysis. Similar responses were counted as an attribute to the key clustered task and the frequencies for each response were counted to get the actual numbers. All the views and discussions that HBC providers felt were expected of them in delivering service were compiled together during analysis and the ten key tasks highlighted are presented on the Table below:

Table 3: Ten key tasks that were mentioned by the HBC providers during FGDs

Responses	Frequency	Percentage
Prepare a report on a monthly basis on the services that have been rendered to the clients	30	100%
Making follow up to establish whether or not the client is being treated for opportunistic infections	25	83%
Providing education on alleviating social stigma	24	80%
Registering clients in home based care services	21	70%
Inspecting clients' medicines; checking their CTC cards to ensure they are sticking to their clinic appointments; monitoring clients and looking for ways on how to involve them in their treatment adherence	16	53%
Advocating on the importance of voluntary counseling and testing	16	53%
Provision of education on family planning, hygiene and nutrition	15	50%
Making follow ups to clients on the usage of ART drugs and discussing with them on the importance of taking their medications	12	40%
Mapping of clients and providing them with education on the importance of enrolling to the CTC programme	12	40%
Raising community awareness on HIV/AIDS issues	12	40%

Findings show that majority of the providers had adequate knowledge on the different tasks that they are supposed to render to clients and the vital importance of these tasks. According to the findings all the providers mentioned preparing monthly reports as one of the key task that each provider is expected to do when providing HBC services. Another 83% mentioned making a follow up on whether the client is being treated for opportunistic infections as another key task as they were in addition expected to provide practical nursing care skills and emotional support. Furthermore 80% of the respondents revealed that they provide education on social stigma considering the high levels of stigma which face the disease which as a result

hinders those living with the disease to disclose their status or to discuss the disease. Further discussions suggested that the HBC providers viewed these services have been used as an opportunity to reduce stigma; influencing people's willingness to know their HIV status as well as changing behavior through awareness raising. Another 70% of the respondents revealed that they register clients into HBC services, a pre-requisite for anyone who wanted to benefit from HBC programmes. HBC providers also revealed how they address the needs of the individuals in the home setting and shared their views about how HBC services have contributed in prevention efforts by involving community members in treatment efforts which has brought issues surrounding the disease into the open. These findings are supported by a study that was done by WHO and UNAIDS 2000 on Operational Challenges for CHBC programmes which highlighted some the care and support activities that HBC providers render include provision of nutrition support, nursing care, psychosocial support, engaging in community activities that reduce stigma and discrimination and provision of health education

Some HBC providers who are also HIV positive shared their experiences in the delivery of HBC services as they serve as expert patients and have been powerful advocates and educators of those starting therapy. They are seen as live examples and give living testimonies of how ARTs have changed their lives. The following narrative statements indicate the experiences of HBC providers in view of their day to day tasks in rendering services:

"Provision of education on hygiene and psychosocial care support"

"Provision of nursing care, symptom and care management and ART adherence support"

"Making assessments to make sure clients are taking their pills appropriately"

"Provision of health education on the importance of adhering to drugs"

"Doing home visits and tracking clients who have missed appointment or those who are loss to follow up"

Generally from the views that were shared by HBC providers on their tasks, it showed that they were the primary community care supporters and educators.

Sub-Theme1.2: HBC providers' knowledge on ART drugs

HBC providers being the direct link between the client and the health facility in tracking ART adherence, it was hence important to assess their knowledge and understanding about ART drugs. This is because among the many tasks that they do when they visit clients at their homes, they conduct pill counts to ensure that clients are taking their pills appropriately and also provide appropriate health education. Each provider was asked to respond to what he/she knew about ART drugs and the related responses were highlighted and grouped in the respective clusters, as shown on Table 4 below:

Table 4: Five key responses of the HBC providers on their knowledge on ARTs (n=30).

Reponses on knowledge of ARTs	**Frequency**	**Percentage**
ARTs are life prolonging drugs	18	60
ARTs give someone hope about their life and gives them an opportunity to even set goals about their life	17	57
ARTs help to improve the body's immune systems and restore the health status of the client	15	50
ARTs restore the value of a person from that of a disease to good health which at the end enables the patient to continue with their daily activities. Patients who were bedridden gain strength and can continue with other activities	7	23
ARTs act as a protection for those cells which have not been affected	2	7

According to the analysis above, HBC providers did not seem to be adequately knowledgeable ARTs since only 60% of them were are that ARTs are life prolonging drugs. Slightly more than half of them (57%) classified ARTs as drugs that give hope to AIDS patients, enhancing their quality of life and enable them to set goals about their life. Another 50% articulated that ARTs help to improve the body's immune system and also helps to restore the health status of the clients. In a similar study that was conducted in Namibia by Niikondo et al (2011); it was observed that the respondents had some general knowledge on HIV/AIDS but it highlighted a lack of knowledge on ART among those who participated in the study. The study concluded

the need for HBC organizations to put emphasis on training HBC care givers on ART and issues of adherence.

Sub-Theme: 1.3: Overview of the changing roles of HBC providers after the introduction of ARTs

HBC services have gained momentum in Musoma Municipal, where the services are now available in all the wards in the district and with the increasing availability of ART drugs, all public health facilities in the region are providing ART to more than half of the population in need of ART's in the district. With this new breakthrough, there have been changes in the context of HBC service delivery where more efforts have been directed towards coping with the increasing burden of patients that need to be accommodated in health facilities but with the fragile health care systems, they have failed to provide the much needed support. Health care providers acknowledged the changing roles of HBC service providers who were said to have become more medicalised. In addition to the care and support they provide in the households, they are now directly involved in enabling and sustaining PLWHA to access ART. With the changing roles their tasks include identifying, referring and accompanying patients for testing and initiation on ART treatment as well as monitoring and provision of adherence support. They also acknowledged that HBC providers have made it easier to reach patients by visiting them on a regular basis, whereas they have taken over the community tasks that used to be done by health care providers. This was evidenced by a huge return rate of patients back into care as a result of efforts by HBC providers.

In a similar study that was done in Zambia which looked at the changing roles of HBC providers, it was observed ART roll-out has resulted into a shift on the roles of HBC providers from solely providing psychosocial, hygiene and nursing care to include adherence support and linking PLWHA with ART clinics (Cataldo, et al 2008). The study looked at the impact of the ART roll-out on the acceptability, roles and relationships of HBC providers with health care providers and their clients. They are seen as extensions of the health care services by fulfilling monitoring and surveillance roles, with clinic staff acknowledging their support in enabling access and adherence to ART. With these changes, it has necessitated the

engagement of HBC providers in the treatment care and support of ART adherence. Table 5 illustrates the changing roles in the delivery of HBC services as revealed in this study:

Table 5: Reported roles of HBC providers before and after the introduction of ARTs

Roles of HBC Providers before ARTs	**Roles of HBC Providers after introduction of ARTs**
Awareness raising and provision of education on issues of HIV/AIDS	Tracking missed appointments and clients who are loss to follow up
Addressing stigma towards the disease	Provision of nursing care
Address clients views on the issue of HIV/AIDS	Providing medical care and the use of different drugs such as skin ointments, painkillers
Patient care focused more on encouraging patients to get tested to know their health status	Provision of advice on prevention of new infection
Encouraging patients to get tested and receive results to enable them initiate treatment on time. .HBC providers were only able to give Septrin for opportunistic infections.	Provision of supportive services, making referrals and giving directions to the health facilities
Provide counseling on testing	Provision of advice for those who have not accepted to get tested
Provide awareness on hygiene and nursing care	Provision of health education and the importance of getting tested and knowing ones HIV status
Provision of psycho-social support	Education on the importance and benefits of ART adherence
Symptom management	Awareness raising about HBC programmes
Nursing care	Support and encourage adherence of PLWHA to their treatment regimens
Handling misconceptions in the community associated with HIV/AIDS and ARTs	Support clients to monitor any side effects from their ART regimens and facilitate referral to health facility services for management of adverse reactions
	Provision of counseling and care to PLHIV
	Ensure that patients receive appropriate physical care and treatment by providing treatment and care for mild symptoms at home
	Training family members of PLHIV to provide physical care at home including mild symptom management, nursing care and general hygiene
	HBC providers increasingly support the formal health care system and effectively create linkages between the PLHIV and the health facility.

As highlighted on the Table, before the introduction of ARTs, the roles of HBC providers were only shaped along the provision of services that aimed at combating the wide spread stigma and discrimination of PLWHA, awareness raising on issues of HIV/AIDS, including education on preventive measures and provision of hygiene, symptom management and nursing care. With the rapid scale up of ART, HBC providers are now more engaged in tracking missed appointments, lost to follow-up clients, providing supportive services including referrals to health facilities and ART adherence support, which has been brought out by the shift from hospital care to community care. Health care providers attributed the massive improvement in ART adherence and return rates of PLWHA on treatment and care as largely supported by HBC programmes. These findings are also supported by a study that was done in Malawi by Zachariah et al (2007), on Community support associated with better anti-retroviral treatment outcomes in a resource limited rural district in Malawi which revealed that patients who were offered community support showed better survival and retention in care rates compared with patients who did not receive such support.

Sub-theme 1.4: Integration of HBC services into the formal health care system

The effectiveness of comprehensive HBC programmes depends on their ability to create well functioning partnership for provision of continuum of care, especially since the epidemic has overwhelmed health care systems. As the number of PLWHA increases, the gap continues to widen between the demand for and the availability of health care services. HBC has become a significant contributor in the provision of continuum of care services to those infected and affected by the disease which has helped health facilities to provide their services more efficiently by maintaining strong links with patients through HBC providers in the communities. Health care providers expressed their views regarding the lack of integration of HBC services into the formal health care system. Despite the lack of formal integration, there still exists a linkage between health facilities and the community volunteers. With this linkage it has also enabled a two way referral to take place, with clients being referred from the CTC and encouraged to join HBC programmes to ensure a continuum of care. Health care providers acknowledged the existence of a provider linkage and referral strategy through which all HBC providers have been linked to health facilities in Musoma Municipal. They also revealed that

the names for HBC providers who are linked to health facilities are made available on the bulletin boards of health facilities in the CTCs and the HBC teams. With this linkage HBC providers are scheduled for half day sessions on a monthly basis at the health facilities for provision of education on adherence counseling and also to see if there are any clients who have either missed appointments, defaulted on their treatment. This linkage has made it easier for them to refer clients to specific HBC providers who live in the same locality.

HBC providers expressed their views that it was important for them to be recognized as a cadre of the health care system as lamented by one FGD participants: *"It is important for HBC services to be integrated into the formal health care system as this will improve service provision systems or approaches which in turn will improve the health facility and community environment support services"*

On the other hand, health care providers expressed the need for the public health care policies to consider the changing context of HBC services as a strategy to support ART adherence by considering the changing roles of HBC providers. Integration is of paramount importance because PLWHA have multiple needs that need to be addressed through comprehensive care. HBC providers also highlighted the need to build a strong and sustainable health care system that incorporates the community component so as to strengthen community care systems, which will in turn ease the workload of health facilities and eventually improve the treatment adherence.

A study that was done in Ethiopia on Determinants of adherence to ART treatment similarly revealed that the quality and characteristics of health services are greater determinants of adherence (Ayalu et al, 2012). This study suggested that in order to increase adherence, health care providers should consider treatment strategies that place a greater emphasis on community social support systems. This study has been backed up by HIV/AIDS programmes which have implemented HBC either within or outside the traditional health care systems to support these proposals for integrated health care settings. This integration can be done to provide the support by shifting certain tasks of health care providers to HBC providers especially in this era of ART roll-out.

THEME2: Perceptions of health care providers towards HBC service providers in facilitating ART adherence

Health care providers overwhelmingly talked about the positive effects ART has had on their clients and the resulting decrease in their workload. They acknowledged the important tasks that HBC providers play in supporting HIV positive clients whereby their tasks have changed since the introduction of ART in the region. HBC providers now play a vital role in supporting the formal health care systems in providing support and monitoring of ART. They also revealed that the roles of HBC providers have changed from those of behavior change to more of provision of support in advocating the importance of PLWHA adhering to their clinic days and their treatment regimens. Some of the narrated perceptions are as indicated below:

"HBC providers increasingly support the formal health care systems by creating linkages between the client and the health facility"

"The roles of HBC have become more medicalised since the introduction of ART as their roles have shifted from just focusing only on the community care activities"

"HBC providers play a great role in following up patients who are loss to follow up and tracking missed appointments whereas there is a huge return rate of clients returning back to CTCs after being tracked"

"HBC providers play an important role of tracking defaulting ART patients and providing them with counseling and return them to treatment"

"HBC providers have taken over the community tasks that were being done by health care personnel which was very overwhelming for them and with the shortage of human resources in the health sector, HBC providers have provided the much needed support to health care providers"

"HBC providers have assisted to increase access to and use of health care facilities through referrals"

"HBC providers support health care workers in delivering services to the communities through a continuum of care

These findings are supported by a similar study by Gupta da Silva and Passos (2005), in Brazil which recommended that HBC providers be used to provide adherence support to patients. HIV positive clients who participated in that study admitted that HBC providers assisted them in adherence management by doing home visits and identifying patients in need of care, tracing social problems affecting them and referring patients to health facilities. The study also revealed that HBC providers have been accepted in the community as they have helped to shape the experiences of PLHWA to treatment and adherence. In addition, HBC was identified as one of the innovative options that could be used to deal with the resulting challenges that are caused by the weak health care systems.

The perceptions of the health care providers towards HBC services reflect the need for HBC to be part of an integrated system that is formally linked to the health care systems for HBC to be effective in supporting ART adherence. Also by having a formal integrated system will make it easy to have a two way referral system between health facilities and the community that works together to address the adherence obstacles. In this regards community based programmes such as HBC programmes have been advocated by both the health care providers and clients as a required mechanism that provides community support which needs to be integrated into the care and treatment package. Health care providers also attributed HBC services as a solution that can help to reduce the burden on health facilities by shifting certain tasks to community providers. This task shifting of the roles of HBC providers should be accompanied by the renewed interest on the role of lay community workers who can be used to provide some of the services that are needed by PLWHA. In particular comprehensive HBC programmes are proving to be the best strategy for ensuring a continuum of care and support to PLWHA outside the health facility environment. The benefits of HBC programmes that incorporate ART adherence support have been reported to work well in countries such as Botswana in a study that was conducted on HIV/AIDS Care: Investigating the value and impact of Community Home Based Care (Browning 2009), and also in another study that was done in Uganda on Assessment of home based care programmes: Their strengths and

weaknesses whereby HBC providers have been used as community linkage workers who support health facilities with community support services including ART adherence.

Systematic reviews have indicated that the most important and frequent factors that impact adherence are the failure of health facilities in having the capacity to conduct patient monitoring due to inadequate human resources. In a study that was done on The Effect of home follow up visit in enhancing ART adherence among HIV/AIDS patients in a rural setting in Malawi (Kamera, 2011) high levels of adherence to treatment regimen were attributed to the deployment of treatment helpers. To a large extent many of the studies that have been done have advocated the roles of the treatment helpers as very important in the interventions that seek to overcome non-adherence obstacles by increasing accessibility to ART treatment support and other health services leading to increased ART adherence. In another similar study that was done in rural Uganda on patients adherence, it reported that good adherence to ART was achieved in a HBC programme, whereby the study reported that 82% of the clients who had good adherence attributed this to being part of an HBC programmme that deploys providers on a weekly basis to make follow up on patients. The participants in the study also cited intensive adherence counseling and support management as factors that have facilitated the good rates of adherence. In particular comprehensive HBC programmes are proving to be the best strategy for ensuring a continuum of care and support to PLWHA outside the health facility environment. Health care workers attributed HBC providers as a new support system that complements their work, and has made it easier to focus on the health needs of the clients leaving the community component to HBC providers.

THEME 3: Perceptions of clients enrolled in ART services towards HBC programmes in supporting ART adherence

ART has transformed the lives of PLWHA as they have become healthier and have resumed their economic and social activities (HIV positive client). For ARTs to be successful maximal and durable suppression of viral replication is needed for the drugs to work well, hence adherence is critical. This requires patients to devote their time, energy and resources to adhere to their treatment requirements, which means regular clinic visits for refilling of their

medicines and conducting assessments of their health status. In this study, HBC providers were singled out to have had a big contribution in ensuring adherence among programme beneficiaries.

Sub-Theme 3.1 Client's knowledge of HBC services

All the clients acknowledged that HBC was not a new concept in their environment, as this concept has been in existence in the African settings for many years. They also shared their understanding that when HBC was introduced in their communities it was the expectation that the provision of care for the sick would be provided within the family and community settings as this would enable the patient to be cared for in a familiar environment. HBC services involve the provision of comprehensive care and social services, by formal and informal caregivers as the services extend from the health facilities to the community and vice versa through referrals. The clients responded further on HBC services as those services that facilitate patient follow up and they also attributed the services have helped to reduce stigma and discrimination through community awareness. Table 7 highlights the key responses on the knowledge of HBC services among clients who are on ART.

Table 6: Five key responses on knowledge of HBC services among clients who are on ARTs

Clients responses (n=16)	**Frequency**	**Percentage**
Home based care is the provision of health education including ART adherence in the home setting	9	56
HBC services is the follow up of clients at their homes which is done HBC providers, where they check on the patients health and wellbeing and also provide pain killers to the patients in their homes	7	44
Home based care services is the care that one receives in the home setting and enables the client to get medical treatment including the provision of pain killers, skin ointments and vitamin tablets	5	31
HBC services have helped to raise awareness on issues of disclosure	6	38
HBC services provides adherence counseling and support to ensure drug adherence	6	38

According to the table above there is a variation in the knowledge and understanding of clients towards HBC services, with 9 of the 16 clients (56%) saying that HBC is the provision of health education including ART adherence in the home settings. Less than half of them (44%) comprehensively narrated HBC services as follow up of clients at their homes whereby the HBC providers check on clients' health and wellbeing and also providing them with pain killers at their homes. This indicates that HBC services as a community support structure is a concept that was not new to the majority of the clients. In a study done in Namibia on PLWHA and the utilization of HBC services, findings revealed that unlike the HIV clients in Musoma, their colleagues in Namibia were knowledgeable about HBC services, (Oguntibeju, et al 2011). However, in both of these studies, clients valued the assistance they received from HBC providers which they think has enhanced their positive attitudes towards the utilization of the services.

Sub-theme: 3.2 Client's views on ART adherence

With the national roll-out of ARTs many PLWHA have experienced improved health as many of the bedridden patients have regained their strengths as a result of using the drugs. ART treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections for PLWHA and in the absence of a cure for HIV/AIDS. Despite this one of the main obstacles to the successful scale up of ART treatment is non-adherence to treatment regimen.

PLWHA shared their views towards ARTs and how it has helped them to improve the immune system. Whereas they acknowledged that for it to be effective it was important to accept the disease and make ARTs part and parcel of one's life by looking at the benefits of what the drugs can do to improve a person's wellbeing. They also revealed that it was important to take into consideration the advice that one is given by the health care providers when they are starting ARTs. Their views on ART adherence have been narrated below:

"ART adherence is not an easy thing but with the benefits that we receive it just forces us to stick to the advice we are given by health care providers"

"When you start taking ARTs in the beginning its difficult and it is really easy to forget to take your medicines but as time passes by you start to get used to it and it gets easier as time passes"

"The important thing is to develop a personal plan or having someone remind you to take your medications"

Despite this importance, PLHWA still acknowledged that it was not easy to maintain adherence especially considering the fact that these are life-long medicines and they must be taken every day. Despite some setbacks in maintaining adherence, clients attributed their ability to maintain good adherence with the help of community support programmes such as HBC. Their views are supported by a randomized study that was conducted in Kenya in 2011. The main observation from this was that patients who received regular adherence counseling through community support providers who visited them and encouraged them to adhere to their medication were 29% less likely to have poor adherence and 59% less likely to have virological failure compared to those who did not. Knowledge and information about the importance of ART plays a key role in patient's adherence towards their treatment regimen and evidence has suggested that patient's adherence is better when the patient believes ART is effective and that non adherence can lead to viral resistance.

Sub-theme 3.3: Client's perceptions towards HBC providers' supporting ART adherence

HBC services are seen not only as an option to alleviate the burden of hospital care for PLWHA but also as an effective entry point into care. Community based programmes by their nature of being in the community have the access needed to track and monitor clients in the community and provide continuous adherence support. With the rapid expansion of services to support continuum of care, the use of HBC services as a core service in care and treatment remains critical in decreasing the number of defaulting ART patients. Clients acknowledged the contribution of HBC providers who make regular follow up visits and monitoring of clients to supporting them with adherence. They were of the opinion that these providers are best placed to provide education, adherence counseling and emotional support to them so as to enforce adherence. The study revealed that HBC providers are often the only source of help

for the patients on ART given the state of health facilities and as they provide the basic adherence education. This is because ART has improved the lives of PLWHA hence there is a need for the health care systems to accommodate this new improvement. Community HBC programmes have proven necessary in providing the community outreach that health care systems cannot provide. Client's perceptions towards HBC providers in supporting ART adherence have been narrated below:

"HBC providers play an active role in monitoring the patient's CTC cards and follow up of their health status and monitoring the changes".

"HBC providers have helped clients to tackle the issues of disclosure which has in turn enabled them to be more open about their status which in turn has improved their adherence."

"HBC providers being the direct community link have played a big role in enrolling clients into care by giving them referrals to the health facility"

"HBC providers provide education to clients on the importance of maintaining ART adherence so as to ensure their treatment regimen is sustained"

"HBC providers who are also PLHIV play an active role in enforcing those clients who they are overseeing adhere to their regimen as they also understand the barriers for enforcing adherence where they act as role models by showing other clients that adherence is possible".

"HBC providers who are also HIV positive understand the barriers faced by PLWHA in adhering to HIV treatment, therefore they are able to provide advice on how to overcome these barriers using their own experiences towards adherence".

These findings are supported by a study in Ethiopia which revealed that HIV clients received satisfactory care and support from HBC providers. The most frequently provided care included home based counseling, nursing care and provision of medical treatment and this support was seen to contribute to good levels of adherence.

Sub-theme 3.4: Overview of the changing roles of HBC providers with the introduction of ARTs

PLWHA attributed the important roles that HBC providers play in health promotion as well as in providing them with assistance on how to deal with the barriers they face on adherence. They also acknowledged HBC as an effective supportive strategy for ART adherence. They highlighted that HBC services have raised awareness among community members about HIV/AIDS, and it has helped to reduce related stigma, myths and misconceptions. According to a research that was done in Zambia on Lay Workers vital role in supporting ART roll-out (DFID 2010), the need to provide recognition and strong evidence on the important roles that HBC providers play in supporting the formal health care systems in advocating and monitoring ART adherence was documented. The study further revealed the changing roles of HBC providers where they act as extensions of the formal health care systems through promotion of HIV care outside the formal health care system. Some of the health care providers in the Zambian study had the following to say: *"The Zambian formal health care system increasingly relies on an army of lay health workers as these play a vital role in supporting the formal health care systems"*. Findings from the Musoma Municipality study relate closely to the observations in the Zambian study.

Another closely related study done in Cambodia on the Changing role of home based care in the era of ART observed that in the era of increased access to ART, there was an increasing demand for health facility based care to provide ART to more than half of the population. As a result of this, the health facilities were overburdened with the demand; hence there was a need to change the roles of HBC providers to provide health facilities the much needed support. The study reveals the Cambodian government had to seize the opportunity to maintain the community strength of HBC and adapt its role to the evolving needs to support the scale up of ART.

THEME 4: Challenges faced by Home Based Care Providers

HBC has received wider attention in the country for its ability to provide a continuum of care for PLWHA in a comprehensive manner. It has been hailed for reducing congestion in hospitals, reducing the burden that health facilities face with the increasing numbers of PLWHA. These services have proven to have the potential to improve uptake of HIV testing and access to care and support. HBC providers are best placed to provide education and emotional support to patients and household members in improving the quality of care and ensuring PLWHA maintain adherence to drug regimens. Despite the work that they do in supporting the formal health care systems they are still faced with challenges in executing their services including lack of recognition of their roles and remuneration and therefore affect their motivation. Some of the challenges facing HBC providers were narrated as follows:

"Inadequate motivation and incentives as such as transport allowances, HBC providers revealed that they lack morale in the work that they are doing as they are treated as volunteers even though they spend a big part of their time doing community support services"

"Lack of resources to help them to conduct their supportive supervision activities such as lack of bicycles, low transport allowances"

"Home based care services do not provide material support such as food aid and still advocate for people to take their medications and adhere to their regime, as a result this makes it difficult for them to advocate the importance of adhering to treatment as in some cases people have not eaten for days"

"When people start to take the drugs and once they get better, they stop taking their medication and continue to live their lives as if they have been cured from their illness"

"Lack ways of addressing the needs of clients who resume active lives on ART but still face a lot of challenges staying on treatment"

"*Poor retention of home based care providers who are in home based care programmes, as a result hinders its sustainability"*

"Home based care providers carry an insurmountable burden of being expected to provide a service with very limited resources and in most instances finding themselves utilizing their own resources because of the client realities that they are faced with"

The HBC providers attributed these challenges to the fact that many of community programmes are implemented through external support of donors and hence lack sustainability. These challenges have also been highlighted in a study done by Evidence for Action on HIV treatment and care system which focused on new challenges faced by home based care givers which revealed that in Sub-Saharan Africa, HBC remains to be an intervention that has low visibility and no formal recognition as observed by HBC providers who were.. They further lamented on their dissatisfaction that the acquisition of skills to support ART adherence is not matched by a formal change in their status. The study concluded that the lack of training, remuneration and recognition of their support contributes to demotivation and poor retention.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.0 Conclusions

On the basis of these research findings, effective ART scale up that ensures adherence management cannot be successful unless they incorporate community support programmes such as HBC programmes. Strong community support structures have long been considered as a cornerstone of effective primary health care delivery, whereby the roles of HBC programmes need to be maximized and the roles of HBC providers acknowledged in order to bridge the gap which exists between the formal health services and the community. The study findings indicate that the roles of HBC providers have changed and they are now heavily involved in supporting ART adherence. HBC providers are being used to complement the weak infrastructures and the paucity health services in dealing with the increasing numbers of PLWHA in the advent of ART.

Further findings revealed that HBC providers are faced with a number of challenges including lack of motivation and the inherently lack of integration of HBC programmes into the health facilities and these scenarios hinder their performance. This unofficial and invisible task shifting of the roles that HBC providers play needs to be valued, supported and validated for the support it provides to the health systems.

5.1 Recommendations

The national care and treatment policies and strategies have put a significant pressure on the health care systems to expand access to ART and this has increased the demand for health services. The rolling up of these ARTs has therefore generally constrained the ability of health care providers in rendering effective services. In this regard the following are the recommendations based on the study findings and conclusions:

1. HBC programmes should be used as a strategy to support adherence management across all health facilities in the country that are providing ART drugs

2. Further research should be done to expand on the findings of this research on how HBC can be used as a key influential factor for adherence interventions in order to develop evidence based interventions for promoting sustained adherence
3. Continuous operational researches should be done on adherence support strategies since adherence is dynamic and complex and therefore multi-dimensional approaches are required to tackle the effectiveness of community support structures in ART adherence

LIMITATIONS OF THE STUDY

For any research that is done there is bound to be some limitations and this study was no exception. Hence a major limitation was that fact that this study was done in Musoma Municipality whose HBC programme works like a project through donor funding and HBC providers might have quite different motivations and therefore more commitment to providing services and consequently not representing comprehensive views of HBC providers elsewhere.

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APPENDICES

APPENDIX I: INFORMED CONSENT, ENGLISH VERSION

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES: DIRECTORATE OF RESEARCH AND PUBLICATIONS

INFORMED CONSENT

Consent to participate in this study

Greetings my names is……I am working on this research project with the objective of finding out whether Home Based Care services can be used as a strategy to support Anti-retroviral adherence, in Musoma Municipal Mara region.

Purpose of the study

The purpose of this study is to collect information on the views and perceptions of People living with HIV/AIDS, health care providers and home based care providers towards home based care services, and how the services can be used to support ART adherence. You are being asked to participate in the study because you have particular knowledge and experiences that may be important to the study.

What participation involves

If you agree to participate in this study the following will occur:

1. You will sit with an interviewer and have a guided discussion . The interviewer will be recording your responses with a tape recorder and also taking notes of the discussion
2. You should know that, no identifying information will be collected from you during the interviews and discussions
3. You will be interviewed once for approximately 40 minutes in a chosen location

Confidentiality

I assure you that all information collected from you will be kept confidential. Only people working in this research study will have access to the information. We will be compiling a report, which will contain responses of the interviews and discussions from several people who have participated in the research. Your name/s will not appear or other identifying information on the records of the information you provide.

Risks

You might be asked questions about issues that might make you feel uncomfortable; you may refuse to answer or discuss any particular issue/s.

Rights to Withdraw and Alternatives

Taking part in this study is completely your choice. If you chose not to participate in the study or if you decide to stop participating in the study you will not get any harm. You can stop participating in this study at any time even if you have already given your consent. Refusal to participate or withdrawal from the study will not involve any penalty or loss of any benefits to which you are otherwise entitled.

Benefits

The information you provide will help to increase our understanding on how Home Based Care services can be used as strategy to support ART adherence. This will enable us to improve on the existing programmes in view of the changing roles that HBC can provide to support ART adherence

In case of injury

We do not anticipate any injury/harm will occur to you or your family, as a result of your participation in this study.

Who to contact

In case of any inquiries/questions, you can contact the Director of Research and Publication Muhimbili University of Health and Allied Sciences (MUHAS), P.O. Box 65001, Dar es Salaam.

Participation

Do you Agree YES…….NO……..

I have read and understood the contents in this form. I agree to participate in this study.

Signature of Participant ……..... Date……

Signature of Principal Investigator……...Date…….…….

APPENDIX II: INFORMED CONSENT KISWAHILI VERSION

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES:

DIRECOTORATE OF REASEACRH AND PUBLICATION

FOMU YA RIDHAA

Ridhaa ya Kushiriki katika utafiti

Habari, jina langu ni ……., nafanya kazi katika mradi huu wa utafiti wenye lengo la kuchunguza kama huduma za wagonjwa nyumbani zinaweza kutumika katika kuhakisha watu wanaotumia dawa za kupunguza makali ya virusi vya UKIMWI wanazingatia masharti yanayoendana na umezaji wa dawa hizo.

Malengo ya Utafiti

Utafiti huu una lengo la kukusanya maoni kutoka kwa walengwa watumiaji wa dawa za kupunguza makali ya virusi vya UKIMWI, watoa huduma za afya na wanaotoa huduma za wagonjwa nyumbani katika wilaya Musoma mjini, mkoa wa Mara. Unaomb wa kushiriki katika utafiti huu kwa sababu unauelewa na uzoefu ambao unaweza kuwa wa muhimu katika utafiti hii.

Ushiriki wako utahusisha nini

Ukikubali kushiriki katika utafiti huu utafanya yafuatayo:

1. Utakaa na msaili/mtafiti kufanya mazumguzmo yanayohusu ufahamu wako
2. Hakuna taarifa zozote za utambulisho tutakazokusanya wakati wa utafiti huu.
3. Mahojiano haya yatachukua takriban dakika arobaini, kwenye seheme yenye utulivu.

Usiri

Nakumbushia kwamba taarifa zote zitakozokusanywa kutoka kwako zitakua ni siri, ni watu wanaofanya kazi katika utafiti huu tu ndio wanaweza kuziona taarifa hizi. Tutajumuisha ripoti ambayo itakua na majadiliano kutoka kwa washiriki mbali mbali bila kuweka utambulisho wowote. Hatutaweka jina lako wala taarifa yoyote ya utambulisho kwenye kumbukumbu za taarifa utakazotupa.

Madhara

Tutafanya mazungumzo juu ya ufahamu wako wa huduma za wagonjwa nyumbani na matumizi ya dawa za kupunguza makali ya virusi vya UKIMWI. Baadhi ya maongezi au maswali yanaweza kukufanya usijiskie vizuri. Unaweza kukataa kujibu swali au kuongelea swala lolote na unaweza kusimamisha usaili wakati wowote.

Haki ya kujitoa na mbadala wowote

Kushiriki katika utafiti huu ni uchaguzi wako, kama utachagua kutoshiriki au utaamua kusimamisha ushiriki wako, hautapat madahara yoyote. Unaweza kusimamisha ushiriki katika tafiti hii muda wowote hata kama ulisharidhia. Kukataa kushiriki au kujitoa kwako katika utafiti, hakutaambatana na adhabu yoyote au upotevu wowote wa faida yoyote unayotakiwa kupata.

Faida

Taarifa utakayotupatia itasaidia kuonegeza uelewa wetu wa juu ya huduma za wagonjwa nyumbani na jinsi gani zinaweza kusaidia utekelezaji wa matumizi ya dawa za kupunguza makali ya virusi vya UKIMWI kwa wale wanaotumia. Pia itatusaidia kuboresha huduma ambazo zinatolewa kwa sasa, kwa kuangilia mabadiliko yaliyojotokeza kutokana na matumizi ya dawa za kupunguza makali ya virusi vya UKIMWI.

Endapo Utadhurika

Hatutegemei madhara yoyote yatatokea kwa kushiriki kwako katika tafiti hii.

Mawasiliano

Kama una maswali kutokana na tafiti hii, unaweza kuwasiliana na Mkurugenzi wa Utafiti na Uchapishaji, Chuo Kikuu cha Muhimbili S.L.P 65001, Dar es Salaam.

Sahihi

Je unakubali kushiriki kwenye tafiti hii?

Mshiriki amekubali

Mshiriki amekataa

Sahihi ya mshiriki ……

Sahihi ya mtafiti mwandamizi ……

APPENDIX III: KEY INFORMANT INTERVIEW GUIDE WITH HEALTH CARE PROVIDERS

1. For how long has this facility been providing ART?
2. What challenges is the health facility facing in providing ART?
3. What do you think can be done to overcome these challenges?
4. What can you say about adherence to ARTs among patients attending this facility?
5. What is the relationship between HBC providers and the formal health care system?
6. What are your perceptions towards HBC providers?
7. What support do HBC providers give to HIV/AIDS clients to ensure ART adherence?
8. What do you consider to be the necessary changes to enable the HBC providers to perform their roles better?

APPENDIX IV: KEY INFORMANT INTERVIEW GUIDE WITH HEALTH CARE PROVIDERS IN HEALTH FACILITIES (KISWAHILI VERSION)

1. Je kituo hiki kimekuwa kikitoa huduma za dawa za kupunguza makali ya Virusi vya UKIMWI kwa muda gani?
2. Je ni changamoto zipi ambazo kituo cha afya kinazipata katika kutoa dawa za kupunguza makali ya Virusi vya UKIMWI?
3. Je unafikiri nini kifanyike ili kukabiliana na changamoto hizo?
4. Je unaweza kusema nini juu ya uzingatiaji wa wagonjwa katika matumizi ya dawa za kupunguza makali ya kupunguza Virusi vya UKIMWI?
5. Je kuna uhusiano gani kati ya watoa huduma za wagonjwa nyumbani na mfumo rasmi wa huduma ya afya?
6. Je una maoni gani juu ya watoa huduma za wagonjwa nyumbani?
7. Je ni msaada gani wanaotoa watoa huduma za wagonjwa nyumbani katika kuhakikisha uzingatiaji wa matumizi ya madawa ya kupunguza makali ya Virusi vya UKIMWI?
8. Je unadhani ni ni mabadiliko gani yanahitajika ili kuwawezesha watoa huduma za wagonjwa majumbani kutekeleza majukumu yao vizuri zaidi?

APPENDIX V

FOCUS GROUP DISCUSSION (FGD) GUIDE WITH HOME BASED CARE PROVIDERS

Introduction

I would like to inform you (participants) that your participation will be tape recorded. The information obtained will be treated in absolute confidentiality and will be used only for purposes of this study. The researcher (research assistant) will proceed to introduce the research team. Thank participants for agreeing to participate, explain to them that they all share a common feature which is that they are HBC providers. Explain to them they are here to share their thinking about HBC programmes, the changing roles of HBC services after the introduction of ART's, challenges experienced. Explain the purpose of the study, purpose of this Focused group discussion, reassurance about confidentiality. The researcher will also seek the consent of the participants before proceeding with the FGDs since there will be taping/recording the discussions.

1. How long have you been providing HBC services?
2. Have you attended any training on HBC services?
3. What are your main tasks as HBC providers?
4. How often do you visit your patients?
5. Is HBC integrated with the formal health care system
6. What do you know of ART drugs?
7. Have the roles of HBC providers changed since the introduction of ART's?
8. Do you have any clients who are taking ART's?
9. What support do HBC providers provide to clients who are on ART's?
10. What are your views about ART adherence?
11. What challenges do you face as HBC providers?

APPENDIX VI

FOCUS GROUP DISCUSSION (FGD) GUIDE WITH HOME BASED CARE PROVIDERS (KISWAHILI VERSION)

Utangulizi

Napenda kuwajulisha kuwa ushiriki wenu utakuwa ukirekodiwa kwa ajili ya kumbukumbu, lakini taarifa zote zitakakazopatikana zitazingatia usiri na zitatumika tu kwa ajili ya utafiti huu

Maelekezo kwa mtafiti

Washukuru washiriki kwa kukubali kushiriki katika utafiti, waeleze kuwa washiriki wote wana sifa moja ambayo ni kwamba wao wote ni watoa huduma za wagonjwa nyumbani. Waeleze kwamba wapo hapa kutoa mawazo yao juu ya programu za huduma za wagonjwa nyumbani, kuongelea mabadiliko ya majukumu yao baada huduma za dawa za kupunguza makali ya Virusi vya UKIMWI.

Maswali wa muongozo wa majadiliano

1. Je mmekuwa mkitoa huduma kwa wagonjwa nyumbani kwa WAVIU kwa muda gani?
2. Je mmewahi kuhudhuria mafunzo yoyote ya huduma za wagonjwa nyumbani?
3. Je majukumu yenu ni yapi kama watoa huduma za wagonjwa nyumbani?
4. Je ni mara ngapi kwa juma mnaenda kuwatembelea wagonjwa majumbani?
5. Je huduma za wagonjwa majumbani zimeunganishwa na mfumo wa huduma kwenye vituo vya afya?
6. Je mnajua nini kuhusu dawa za kupunguza makali ya Virusi vya UKIMWI?
7. Je majukumu yenu yamebadilika tangu kuanza kutolewa kwa dawa za kupunguza makali ya Virusi vya UKIMWI?
8. Je mnawagonjwa ambao wanatumia dawa za kupunguza makali ya Virusi vya UKIMWI?

9. Je ni msaada gani mnaotoa kwa wagonjwa ambao wanatumia dawa za kupunguza makali ya Virusi vya UKIMWI kama watoa huduma za wagonjwa majumbani?
10. Je una maoni gani kuhusu uzingatiaji wa dawa za kupunguza makali ya Virusi vya UKIMWI?
11. Je ni changamoto zipi mnazozipata kama watoa huduma za wagonjwa nyumbani?

APPENDIX VII: INDEPTH INTERVIEW GUIDE WITH CLIENTS ON ARTs ATTENDING CTC

Thank the participant for agreeing to participate in the interview, explain to him/her that they are here to share their thinking and views about ARTs, any and challenges they face and adherence to the regimen. Also to get their perception towards HBC services.

Provide short introductory remarks

• Introduction of researchers and participants

• Explain purpose of study, purpose of this discussion, reassurance about confidentiality, agree on rules

Guiding Questions

1. What do you know about HBC services?
2. What are your perceptions towards HBC providers?
3. ARTs are lifelong medicines and should be taken for the rest of one's life, what can you say about adherence?
4. What do you see as the roles of HBC providers in supporting ART adherence?
5. What can you say about the roles of HBC providers changing since the introduction of ART?

APPENDIX VIII: INDEPTH INTERVIEW GUIDE (WITH CLIENTS ON ART's AND ATTENDING CTC's IN SELECTED HEALTH FACILITIES)

Mshukuru mshiriki kwa kukubali kushiriki katika mahojiano, muelezee kwamba yupo hapa kutoa mawazo na maoni yake kuhusu dawa za kupunguza makali ya Virusi vya UKIMWI, changamoto wanazokabiliana nazo katika uzingatiaji wa kumeza dawa za kupunguza makali ya Virusi vya UKIMIWI. Pia kutaka kupata maoni yake kuhusu huduma za wagonjwa nyumbani.

Toa maelezo mafupi

- Toa utambulisho wa watafiti na washiriki
- Elezea lengo na madhumuni ya mjadala huu, mhakikishie juu ya swala zima la usiri, pia kubalianeni juu ya kanuni za kuendesha mjadala huu

Maswali ya kuongoza

1. Je unajua nini kuhusu huduma za wagonjwa nyumbani?
2. Je una maoni gani juu ya watoa huduma za wagonjwa majumbani?
3. Dawa za kupunguza makali ya Virusi vya UKIMWI zinapaswa kumezwa katika maisha yote ya yule mtumiaji, je unaweza kuesma nini kuhusu uzingatiaji wa kumeza dawa hizo?
4. Je unaona ni majukumu yapi walionayo watoa huduma za wagonjwa nyumbani katika kusaidia uzingatiaji wa matumizi ya madawa ya kupunguza makali ya Virusi vya UKIMWI?
5. Je unaweza kusema nini kuhusu majukumu ya watoa huduma za wagonjwa nyumbani kubadilika tangu kuanza kutolewa kwa dawa za kupunguza makali ya Virusi vya UKIMWI? Elezea majukumu yao yalivyokuwa kabla ya kuanza kutolewa dawa za kupunguza makali ya Virusi vya UKIMWI na jinsi majukumu hayo yalivyobadilika tangu huduma hiyo kuanza kutolewa.

APPENDIX IX

SUMMARY OF CLIENTS WHO WERE INTERVIEWED

Client	**Year which client discovered their HIV status**	**Year which client started ART**	**Year which client joined Home Based care services**
Client 1	1995	2005	2006
Client 2	2006	2006	2006
Client 3	2005	2006	2009
Client 4	2007	2007	2008
Client 5	2006	2006	2010
Client 6	2004	2006	2007
Client 7	2011	2011	2011
Client 8	2009	2009	2012
Client 9	2007	2007	2010
Client 10	2003	2006	2010
Client 11	2004	2007	2007
Client 12	2000	2004	2004
Client 13	2004	2007	2007
Client 14	2003	2005	2006
Client 15	2006	2007	2008
Client 16	2005	2007	2007

APPENDIX X

ETHICAL CLEARANCE APPROVAL