EXPERIENCES OF COMMUNITY HOME BASED CARE VOLUNTEERS IN HIV AND AIDS CARE IN DOWA DISTRICT

MSc. Thesis (Community Health Nursing)

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MSc. Thesis (Community Health Nursing)

By

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Declaration

I, Rosemary Miyove Bilesi, declare that this thesis **'Experiences of community home based care volunteers in HIV and AIDS care in Dowa district'** is entirely my own original work. It has not been presented for any award anywhere else. All sources of information that have been used or quoted have been appropriately acknowledged.

..... **……**

Signature **Date**

Certificate of Approval/Certification

The undersigned certify that this thesis represents the student's own work and effort and has been submitted with our approval.

Signature:_____Date:_____

NAME: _____

Supervisor

Dedication

To my husband Yohane Chibaya Bilesi and to our children Ufulu, Mtendere and Wathu, thanks for your love and endurance throughout my study period.

To my mother Phyllis, a retired teacher who instilled the hard working spirit in me, amaiye I love you.

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Abstract

Malawi like many countries in the Sub-Saharan Africa is burdened by chronic and terminal illnesses including AIDS. As more people live with HIV and AIDS, home based care which utilizes community home based care (CHBC) volunteers' remains necessary. The study was carried out with the aim of exploring the experiences of CHBC volunteers in HIV and AIDS care in Dowa district. The nature of the study was exploratory and descriptive which used qualitative methods. Individual in-depth interviews were carried out with CHBC volunteers (n=15). Thematic analysis of the data was done which was guided by framework approach.

Findings of the study showed humane factors as motivators to join CHBC work emerging more than personal factors. There was less patient workload whilst common roles were household chores and basic nursing care. Common sources of support were from within the community but lacked adequate technical support from healthcare workers. CHBC volunteers felt frustrated and helpless because of lacking resources like CHBC kits and transport. This resulted into walking long distances and making money contributions for buying drugs and hiring transport for their patients. The study recommended that District Health Offices (DHOs) should orient healthcare workers on CHBC and conduct integrated supervision for community based health programs including CHBC. Furthermore, CHBC volunteer trainings should continue to enable them handle emerging conditions. CBOs should reduce donor dependency and resort to owning sustainable income generating activities (IGAs) like commercial farming.

Key words: *community home based care, HIV and AIDS, volunteers, CBO, experience*

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List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ARV	Antiretroviral
CBOs	Community Based Organizations
CHBC	Community Home Based Care
CHW	Community Health Workers
COMREC	College of Medicine Research and Ethics Committee
DHMT	District Health Management Team
DIP	District Implementation Plan
DHO	District Health Office
DOT	Direct Observed Therapy
FBO	Faith Based Organization
GOM	Government of Malawi
HIV	Human Immunodeficiency Virus
HRH	Human Resources for Health
HSA	Health Surveillance Assistant
IGA	Income Generating Activity
KCN	Kamuzu College of Nursing
MOH	Ministry of Health
NAC	National AIDS Commission
NSO	National Statistical Office
NGO	Non-Governmental Organization
PHC	Primary Health Care
PLWA	People Living With AIDS
TB	Tuberculosis

UNAIDS	Joint United Nations Program on HIV/AIDS
VAC	Village Action Committee
WHO	World Health Organization

Definition of terms

In the study, the under listed terms have been defined as follows:

Community Home Based Care (CHBC): is the care provided to chronically or terminally ill patients with HIV and AIDS, TB, Cancer, and other chronic illnesses including relatives, friends, vulnerable and at risk groups in their home, family and community using available resources and support from the formal health and social worker

CHBC Volunteer is a common term used in the community to refer to any person who is trained in CHBC to render direct patient care to chronically/terminally ill persons and other vulnerable people in their home. In Malawi, CHBC volunteer is also known as community care provider.

Experience is something that you do or happens to you and it has an effect on what you feel or think. CHBC volunteer experiences will contain what the volunteers do and all what happens to them.

Task shifting: is the process of delegation in which tasks are moved, where appropriate, from more to less specialized health worker.

Volunteerism: is the art of giving oneself to work for the good of others without being motivated by financial gain.

CHAPTER 1

Introduction and background

Introduction

HIV and AIDS continues to be a major health problem. It is estimated that 36.9 million people were living with HIV worldwide in the year 2014 (Joint United Nations Program on HIV/AIDS [UNAIDS], 2015). The number of people living with HIV has been increasing due to the availability of life prolonging drugs (UNAIDS, 2014). New HIV infections were estimated at 2.0 million in 2014 from 3.4 million in 2001 (UNAIDS, 2015). According to UNAIDS (2014), the number of AIDS deaths continues to decline because the number of people who are not receiving antiretroviral therapy has been reduced from 90 percent in 2006 to 63 percent in 2014. AIDS related deaths in 2014, were estimated at 1.2 million, a reduction from 2.3 million deaths in 2005 (UNAIDS, 2015). The world had made progress on HIV and AIDS targets for the United Nations declarations, however challenges still remain. Although the number of new HIV infections is declining, still more the numbers are very high (UNAIDS, 2014).

Sub- Saharan Africa has high burden of infectious diseases amongst which is HIV and AIDS. Mutangadura and Sandkjaer (2009) specified that the southern and increasingly the eastern and central Africa sub-regions are particularly hard hit by HIV and AIDS. The number of people living with HIV and AIDS is estimated to be 25.8 million (UNAIDS, 2015).

In Malawi, several key populations are increasingly vulnerable to HIV infection which include children, women, young people, men who have sex with men (MSM) and sex workers (AVERT, n.d.). Malawi recorded the highest HIV prevalence at 16.4% in 1999 among 15-49 age group (Government of Malawi, 2012). Over the last decade, there has been a decline in the HIV prevalence rate. The prevalence rate among adults was estimated at 10.0 percent in 2014, a decline from 14.7 percent in 2010 (National AIDS Commission [NAC], 2015). In 2014, new HIV infections were 42,000 a decline from 89,000 in 2004 (NAC, 2015). However, HIV is increasing among women because more than half of all new infections in 2014 occurred in women aged 15 and above (NAC).

Children are equally greatly affected by HIV in Malawi. An estimated 170,000 children were living with HIV by 2013 with 16,000 new annual infections (AVERT, n.d.). More than half a million of children have been orphaned by AIDS and poverty that is prevalent in Malawi, hinders adequate support and services to these children. However, Malawi is reported to have had the largest decline in the rate of children acquiring HIV infection by 67 percent (UNAIDS, 2014).

Malawi has seen a decline in AIDS related deaths which dropped to 27,000 in 2014 a decline from 39,000 in 2010 (NAC, 2015). According to UNAIDS (2014) AIDS related deaths were estimated at 3 percent in Malawi. The decline of the AIDS mortality is a result of increased access to antiretroviral therapy. Different HIV prevention works have been instituted guided by the revised National HIV and AIDS policy and the National HIV and AIDS Strategic Plan (2011-2016).

Despite the gains being achieved in the fight against HIV and AIDS, there are challenges which are hampering the progress of the fight. One of the key challenges is shortage of formal health workers (Raven et al., 2015). The crisis of health care workers was considered as an obstacle to achieving health-related millennium

development goals by 2015 (Alam, Khan, & Walker, 2012). This has resulted into WHO's proposal of ''task shifting''. As more individuals are living with AIDS, more people are needed to provide services hence volunteer services are increasingly more valuable (Held & Brann, 2007). Community involvement and participation is key to disease control efforts in Africa (WHO, 2008). The model of volunteer community health workers is therefore a common approach to serving the poor communities in developing countries (Dil, Strachan, Cairncross, Korkor, & Hill, 2012).

Background

AIDS is a chronic illness which requires ongoing care in the home. Community home based care (CHBC) is defined as " any form of care given to ill people in their home which includes physical, psychosocial, palliative and spiritual" (WHO, 2002, p. 9). According to WHO (2002) essential elements of CHBC include provision of care, continuum of care, education, supplies and equipment, staffing, financing and sustainability and monitoring and evaluation. In terms of staffing, CHBC volunteers form part of the CHBC team. The advantage of having the CHBC volunteers in the CHBC team is that they live in the communities and know the population well (WHO, 2002).

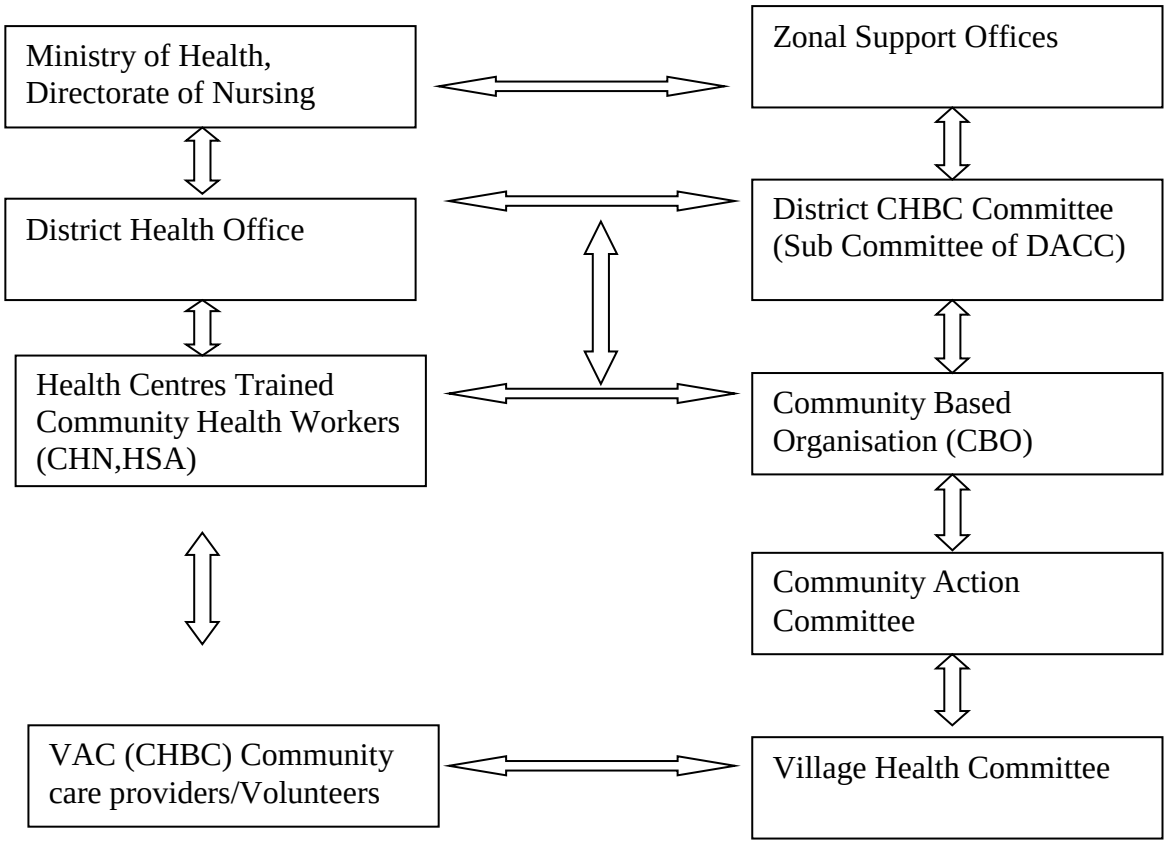
Home-based care programs are mainly initiated by churches, community groupings and non-governmental organizations (NGOs) and few receive support from government. These organizations rely mainly on unpaid volunteers who are recruited from HIV and AIDS affected communities and trained to assist families in their local communities in providing home care for the ill (Akintola, 2010b). In many countries, volunteers participate in programs that provide care for HIV and AIDS patients and their families (Sapountzi-Krepia, Antonakis, Sgantzos, & Lionis, 2003). Most of such voluntary programs cooperate with the formal health care services and are supported

by them. Evidence has shown that CHBC is beneficial to the patient, family and the community. Motswasele and Peu (2008) assert that with the use of home based care, the patient stays in a familiar environment which reduces isolation. The home is also a good environment which meets the needs of dying patients whilst the family and the community is provided with counseling and education about HIV and AIDS (Campbell & Foulis, 2004). It is also a platform for community development and social interaction and generates networks of friendship and support.

Malawi defines CHBC as the care provided to chronically or terminally ill patients with HIV and AIDS, tuberculosis, cancer and other chronic illnesses including vulnerable and at risk groups in the community with support from formal health and social worker (Ministry of Health, 2012). Malawi Government has put down strategies to mitigate the impact of HIV and AIDS through the implementation of the National AIDS framework within which is community home-based care. Community home based care is an important component within essential health package and primary health care.

Munthali (2009) asserts that at the community level, harmonization structure for CHBC include the CHBC groups. These groups have been formed with efforts from a wide range of partners in the HIV/AIDS sector. Commonly found are the local NGOs, Community Based Organisations (CBOs), Faith Based Organisations (FBOs) and support groups. The CBOs have their area network within a group village headman to avoid overlap and duplication of activities. They are registered with the Ministry of Gender, child welfare and social services. They work hand in hand with the village development committees and the area development committees. In addition, they work with the ministry of health because of their involvement in patient care issues. Figure 1.1 shows how CBOs link with other groups including ministry of health.

Figure 1.1: CHBC structure in Malawi



Source: (Ministry of Health, 2012)

CHBC is provided by family members, trained community members including traditional healers, trained extension workers, trained health workers and trained expert clients. In Malawi, CHBC volunteers should be those that are willing and should be selected and accepted by their communities (Ministry of Health, 2011). In addition, they should be committed, reliable and maintain confidentiality. In its design, the Malawi CHBC programme has the trained health workers and Health Surveillance Assistants (HSAs) as supervisors of the volunteers.

The Malawi Ministry of Health has prescribed comprehensive and minimum package of services for community care. CHBC institutions with financial capabilities

offer comprehensive package while most of the groups are expected to offer the minimum package. Within the minimum package, CHBC volunteers are expected to offer basic nursing care, palliative care, community based pre ART care, manage common health ailments in the home, and be able to identify and refer chronic illnesses to appropriate services. In addition they are expected to transfer skills to family members, prevent infections in the home and educate and counsel patients and family members on prevention of HIV, TB and malaria (Ministry of Health, 2011). Recent studies in Malawi have shown that CHBC for chronically ill people like those suffering from HIV and AIDS improves access to health care and support services (Njobvuyalema, 2011; Pindani, 2010).

In order to render effective home care, CHBC volunteers require equipment, drugs and supplies (Global Health Workforce Alliance, 2010). The following drugs are required in the volunteer CHBC kit: panadol, aspirin, multivitamin, vitamin B complex, vitamin B6, vitamin C, and vitamin A and iron tablets. Supplies like ORS, condoms, bandages, gauze square, cotton wool, insecticide treated nets, salt, plastic sheets, gloves, chlorine, soap, plastic apron, and stationery are essentially required (Ministry of Health, 2011).

In South Africa, a study was done which looked at the experiences of HIV and AIDS home based caregivers in Vhembe district of the Limpopo province. The study utilised in-depth individual interviews to collect data. The results showed that caregivers experienced stress and burn out, faced stigma, felt frustrated and helpless (Mashau and Davhana-Maselesele, 2009). A similar study was done in ODI, sub-district in North West province but utilised focused group discussions. Findings indicated that the informal caregivers loved their job but felt exploited as the whole burden of care was left for them (Motswasele & Peu, 2008). The methodology used for both studies was capable of generating rich data but findings could not be

generalized because of small sample size which represented the experience of those study participants in that particular study setting.

Another study was done in Blantyre, Malawi which looked at the motivation of caregivers and it was found that the community caregivers were motivated by religious convictions, altruism and feelings of empathy (Mkandawire & Muula, 2005). The study further reported on caregivers' roles and sources of material support which was reported from the community only. CHBC needs may be many and therefore status of support for CHBC volunteers needs to be established from a wider net other than the community members.

A multi-country research which included Malawi was done on community caregivers as backbone of accessible care and support. Findings depicted that the caregivers supported primary caregivers with household chores, assisted with counselling and psychosocial support and made referrals (Masanjala & Kajumi, 2013). Furthermore, the study revealed that many challenges engulfed CHBC service provision which included drug shortages, weak coordination and reduced funding to CHBC providers. The study had a wider horizon in its exploration which included policy environment and health system integration in HIV treatment apart from looking at caregiver's roles, service provision, acceptance and recognition. Studies that address experiences of CHBC volunteers in HIV and AIDS care are scarce in Malawi. In addition, few studies have looked at specific areas in the experience of the volunteers. It is against this background that this qualitative descriptive study was carried out in order to explore the experiences of CHBC volunteers in the care of HIV and AIDS patients.

Problem Statement

Anecdotal notes indicate that ninety percent of HIV and AIDS patients in Malawi are discharged from hospital to receive ongoing care at home. However, the few studies done in Malawi on CHBC have found that its implementation is facing a lot of challenges. Masanjala and Kajumi (2013) observed that many NGO CHBC providers have scaled down activities due to funding cuts from donors. Similarly, Njobvuyalema (2011) found that funding towards HIV and AIDS support care has dwindled over the years. Most Community Based Organizations (CBOs) and Faith Based Organisations (FBOs) in the districts including Dowa relied on NAC funding which has dwindled. Caregivers are managed through established community structures which include CBOs and support groups (Masanjala& Kajumi). The reduced or lack of external support towards the CHBC groups has affected CHBC volunteers. The foregoing implies that CHBC volunteers deliver care and support to HIV and AIDS patients against a background of inadequate support. This is against the desirables of a CHBC programme which needs to have adequate resources for effective delivery of care. Although studies have been done in Malawi regarding CHBC, little is known about the experiences of CHBC volunteers. The study was therefore carried out to explore the experiences of the CHBC volunteers in the care and support of HIV and AIDS patients.

Significance of the study

CHBC volunteers form an important team in primary health care. The study was justified for a number of reasons. Firstly the study has unveiled the experiences of volunteer caregivers in their work. The experiences surrounding their course of work, needs, support and challenges have been established. The practice of volunteers can improve through the recommendations that have been made based on the

findings. The findings from the study will help policy makers and stakeholders in CHBC to plan for relevant and effective motivation strategies which are evidence based. Motivated CHBC volunteers are likely to offer a good service consequently leading to quality health service delivery in the country.

To other institutions, it will lead to a renewed attention to volunteer needs. This will strengthen the primary health care system and eventually lead into a successful CHBC program. The study shall add onto the research studies in CHBC which has a small coverage at present. Furthermore, the research findings have also provided a basis for conducting further research within CHBC program.

Objectives of the study

Broad objective

To explore the experiences of CHBC volunteers in HIV and AIDS care in Dowa district, Malawi.

Specific objectives

1. To describe factors that motivate CHBC volunteers in HIV and AIDS care.
2. To examine the role of CHBC volunteers in HIV and AIDS care.
3. To identify the available support given to CHBC volunteers in HIV and AIDS care.
4. To describe the challenges faced by CHBC volunteers in their work.

CHAPTER 2

Literature review

Introduction

The existence of HIV and AIDS and other chronic illnesses have resulted in the mobilization, recruitment and provision of training for community members who volunteer their services in the affected communities. This section has provided a review of literature on the experiences of CHBC volunteers. Studies that have explicitly looked at the experiences of CHBC volunteers were few but most of the literature that have been reviewed looked at specific form of experience under motivation and challenges.

The search strategy utilised key words like volunteerism, HIV and AIDS care, community home based care, volunteers, and experiences which yielded many results. The sources of literature were PubMed, Hinari, EBSCO host, African on-line journals and Google scholar databases. The researcher only considered the studies which were appropriate and relevant to this study. Most of literature that had been reviewed was generated between 2005 and 2014. However very few literature as below as 2000 were included having considered their relevance to the study. In some parts of the world CHBC volunteers are referred to as informal caregivers, community care givers, community health workers (CHW) and care facilitators hence such studies have been included. The studies which explored family caregivers were excluded. However, it is important to note that individuals may be both family care givers and voluntary care givers. The literature is on the burden of care that the CHBC volunteers have, their motivation towards care, needs and the status of support and finally challenges of CHBC volunteer work.

Motivation towards caring

CHBC volunteers have been motivated to participate in giving care from a background of different reasons which are both intrinsic and extrinsic. Rödlach (2009) did a study on home based care for people living with AIDS in Zimbabwe: voluntary caregivers' motivations and concerns using qualitative methodology. The study used multiple data collection methods of individual in-depth interviews and focus groups with a large sample size of 220. Data were collected from caregivers, People living with AIDS (PLWA), health care workers and township residents. Findings indicated that the volunteers were driven by religious values. They believed that by helping the sick, they were doing God's work. The use of more than one method to collect data among different groups provided rich data. Another study utilized qualitative methods with individual in-depth interviews only and small sample size with the aim of determining motivation factors for community care givers in Blantyre, Malawi. The results also revealed the same that CHBC volunteers felt obliged by their religious values to take care of the sick (Mkandawire & Muula, 2005). Again another qualitative methods study in South Africa which explored what motivated people to volunteer in faith based organisations found that volunteering to some AIDS caregivers was a fulfillment of their religious teachings and obligation to help others (Akintola, 2010b).The above motivation studies cannot be generalized because of the qualitative designs which they used.

A study done in South Africa also found that motivation derived from compassionate feelings for the helpless where the caregivers become deeply concerned with the helpless situation of people in the community (Akintola, 2008). The same findings were obtained in another study by the same author where the values of giving out help came out (Akintola, 2010b). Rödlach (2009) in Zimbabwe observed that volunteers had empathy which derived from witnessing the suffering

from AIDS. Marincowitz, Jackson, and Fehrsen (2004) in their study utilised focus group discussions to understand what factors helped volunteers to keep on working in South Africa. The authors got similar findings to those of Rödlach that patients had feelings of being sorry for their patients and this motivated them to become volunteers.

Other studies have demonstrated that motivation to volunteer in HIV and AIDS care result from social drives. In a study done by Akintola (2010a), he observed that relating with friends who were already volunteers attracted others to join the work and they never wanted to say no to their friends. Marincowitz et al. (2004) in their study also reported that intrinsic drive to assist own people made it easy for home-based care volunteers to continue with the work. They also observed that the fact that patients got better with their support and appreciated the care was another important motivator. This is similar to findings by Primo (2007) where helping patients to recover and lead normal life was an ongoing motivator.

Studies that have been done also demonstrate that volunteers engage in the work to meet other personal objectives as well. In South Africa, a study was done by Thabethe (2011) qualitative in nature, using focus group interviews in 25 women caregivers. The study revealed that care givers engaged in CHBC activities with the hope of acquiring work experience in order to secure formal job opportunities. However, only women caregivers were involved in the study as a result motivations drives for male caregivers were not represented. This concurs with the results of a health facility based quantitative methodology study which was done in Southwestern states of Nigeria with health facility based volunteers. The results indicated that volunteers in Nigeria were involved in care giving in order to gain job-relevant experience (Adebimpe, Akindele, Asekun-Olarinmoye, & Olugbenga-Bello, 2013). The authors also found that CHBC volunteers were attracted by indirect incentives

like T-shirts. Although the sample size was large, the used study methodology could not give more insight into the motivation experiences of the volunteers because in quantitative designs, use of predetermined tools restricts respondents (Burns & Grove, 2005). In addition, it involved facility based caregivers whose experiences may differ from those of community based volunteers.

Some volunteers were engaged in voluntary work with the hope that in future the same concern would be shown to them when they fell ill. In the past studies most of the volunteers were living with HIV and therefore their motivation was driven by an aim of securing care-giving support in future (Rödlach, 2009). Similarly, others considered that they together with their families might need the same support in future (Primo, 2007).

Few studies have also reported that monetary incentive is a motivator to few volunteer caregivers. In Nigeria, few volunteers were motivated by monetary incentives (Adebimpe et al., 2013). Likewise in Malawi, Munthali (2009) found that few CHBC actors reported that they were being motivated with anticipation of getting monetary incentives in future.

Care burden

The burden of care for HIV and AIDS patients rests heavily on women CHBC volunteers (Akintola, 2004; Njobvuyalema, 2011). Munthali (2009) did a study on institutional analysis of organisations involved in community and home-based care and support for HIV and AIDS patients in Malawi. He found that sacrifices made by volunteers are often difficult to quantify as they came in the form of human resources, time, financial and material contributions in the course of delivering care and support for HIV and AIDS patients. Similarly, Akintola (2008) observed that the majority of

volunteers were unemployed and not remunerated, yet they used their own meager resources to help their patients.

Studies have illustrated that CHBC volunteers conducted home visits where they offer basic nursing care in form of mouth care, bathing, feeding, wound care, turning and lifting of patients and some medical support (Akintola, 2004; Osawa, Kodama, & Kundishora, 2010; Primo, 2007). In addition, they also performed household chores like cooking, drawing water, sweeping home surroundings and providing firewood (Munthali, 2009). CHBC volunteers also made referrals of patients to hospitals (Bowie, Gondwe, & Bowie, 2010; Osawa et al., 2010). Adebimpe et al. (2013) found that most of the volunteers were living with HIV and they offered support and adherence counselling to patients on ART. The findings illustrate that apart from

Another study which aimed at exploring and describing the experiences of informal care givers in home-based care was done in the ODI sub-district area in the North West Province of South Africa. It utilized focus group discussions with 10 participants who were purposively sampled. They found that CHBC volunteers were left with the whole burden of care as such they felt exploited (Motswasele & Peu, 2008). Another study conducted in KwaZulu Natal with 25 women caregivers reported the same to say volunteers were exploited as they did whatever they were requested to do (Thabethe, 2011). The participants were all women and therefore experiences of men caregivers were left out. However, contrary to these findings, Pindani (2010) did a study on the experiences of HIV and AIDS patients on their care and it was found that family members are the ones who provided most of the care. The findings were according to patients' perception. It was therefore concluded from the study that community members should be encouraged by local leaders to participate actively in home-based care.

Pindani (2010) found that most patients prioritized food as their most need. However, most of the households do not have adequate food due to poverty. CHBC volunteers also took the burden of supporting patients with food, usually provided from their own resources (Akintola, 2004; Mkandawire & Muula, 2005; Munthali, 2009). In a study done by Mkandawire and Muula, findings showed that CHBC volunteers were also supporting education of orphans by paying secondary school fees. The latter shows that apart from food support, volunteers were also supporting patient's families with other needs.

Another study done by Akintola (2010a), qualitative in nature with 57 participants studied perceptions of rewards among caregivers of people living with AIDS. The study revealed that the caregivers provided directly observed treatment (DOTS) to tuberculosis patients which they perceived as a reward of gaining skills. While another study done in Malawi, found that volunteer caregivers were also involved in active TB case finding by referring all patients with a chronic cough of 3 weeks or more (Zachariah et al., 2006). It implies that CHBC volunteers assist in TB case finding and administration of TB treatment in some countries which is an expansion on their roles.

Support for CHBC volunteers

Community health workers require support just like any other health worker in order to contribute effectively to health programmes (Raven et al., 2015). In a study done by Motswasele and Peu (2008), it revealed that the community felt pity and supported care by acting like informal care givers themselves. However, the same study reported that family members neglected patients when the caregiver was not there. These findings illustrated that there was inadequate support at family level while members of the general community offered good support. However, the data

collection method used was different from what Mashau and Davhana-Maselesele (2009) did by using individual in-depth interviews for the same purpose of exploring and describing experiences of HIV and AIDS home-based care volunteers. The results were consistent because the latter study also revealed poor support of patients by family members. Some patients were not cared for by family members while other caregivers accepted at the time when the patient's condition had deteriorated. Although the studies looked at the experiences of HIV and AIDS caregivers, the results cannot be generalised because the methodology used small sample size which represented the experience of those study participants in that particular study setting.

Munthali (2009) findings on community support were different from what Motswasele and Peu (2008) found. He found that the community including local leaders perceived that CHBC groups were making money out of their work. As a result, CHBC volunteers were excluded from the community development programs such as "food for work programs''. Similarly, Mkandawire and Muula (2005) in their study found that the communities were not supporting the volunteers with materials towards care of patients. The reasons behind the different picture of community support needs to be established.

From the studies that have been reviewed, little is known on what responsibilities patients take in support of CHBC. In South Africa, a study reported that patients accepted the care that was being offered by voluntary caregivers as a result the patient-caregiver relationship enabled discussion of confidential issues regarding patient's illness (Primo, 2007). In another study done on the same country, patients acknowledged and appreciated the care offered by caregivers which in another way acted as a motivator to the caregivers (Thabethe, 2011).

Support for CHBC also derives from the hospitals or clinics. In South Africa, a study which was done by Motswasele and Peu (2008) reported that CHBC

volunteers received support of food parcels which were given to patients from the clinic. Njobvuyalema (2011) evaluated adherence to the community home based care policy and guidelines using in-depth interviews of ten community volunteers and ten clients and focus group discussions with stakeholders. On the contrary, he found that CHBC volunteers were receiving inadequate support in terms of drugs and supplies (Njobvuyalema, 2011). He further observed that the drugs which CHBC volunteers got could not match with the number of patients. The researcher recommended that CHBC drugs and supplies budget should be included in the district implementation plans (DIP).

Organizations that are involved in home-based care contribute to quality CHBC services through their support. A study done in Zimbabwe which looked at motivation and sustainability of care facilitators engaged in a community home-based care HIV/AIDS programme in Masvingo province found that Red Cross Society supported the care facilitators by delivering organizational goals and gave instructions which motivated the care facilitators (Osawa et al., 2010). Contrary to the findings in Zimbabwe, a study in Kenya revealed that Non-Governmental Organisations (NGOs) did not provide adequate managerial and programmatic support for efficient delivery of care (Takasugi & Lee, 2012). Again the support could perhaps depend on the organizations' financial capabilities sourced from within or outside the organization.

Challenges of CHBC volunteers

Studies have shown that CHBC volunteers face challenges in the course of their work. Mashau and Davhana-Maselesele (2009) in their study in South Africa found that caregivers experienced frustration and feelings of helplessness every day from lack of basic resources and walking long distances to do patient visits. It was reported that some could even walk for 10km in order to get patients under their care.

Takasugi and Lee (2012) had similar findings in their qualitative study done in Kenya. They found that CHWs lacked resources such as drugs and this undermined their work because CHW could not live up to the expectations of the communities. In addition, many participants in the study reported that lack of transportation was a problem especially at night and during rainy season for patient referrals because health facilities were far away from the villages (Takasugi & Lee, 2012). In Malawi, studies have reported on the shortage of drugs for CHBC (Mkandawire & Muula, 2005; Njovuyalema, 2011)

However, another study indicated that caregivers require material, emotional, technical and physical support to discharge their duties effectively. According to Primo (2007), caregivers need sufficient equipment for example masks, aprons, first aid kit and increase in stipend. Primo further alludes to the fact that caregivers need registration, advanced counselling, debriefing, support groups, counselling sessions, stress relief sessions, transport for patients, clinic services on farms, financial support, for example from the government and private sector. Rödlach (2009) in Zimbabwe found that the small remunerations that the volunteers received contributed to the welfare of their families.

Mashau and Davhana-Maselesele (2009) also reported that there were problems of stigma in the first visits as patients could not welcome home-based caregiver but they accepted them in the subsequent visits. Akintola (2005) similarly reported that volunteers bemoaned poor reception by patient's families which later improved with repeated visits. Studies have also shown that discouragement did not only come from patients but also from the community members. Friends and neighbours gave discouraging comments which suggested that the volunteers were irresponsible by being involved in a non-paying job during home visits. As a result CHBC volunteers could end up in emotional stress (Akintola, 2005).

Schneider, Hlophe and Rensburg (2008) in their study done in South Africa, found that community health workers perceived that their contributions lacked recognition by healthcare personnel and communities. The study further revealed that the lay health workers had unsupportive environment, lacked appropriate incentives and were poorly supervised. This led to other problems of poor quality care and high turnover. Adebimpe et al. (2013) echoed the same findings that there was poor technical and supervision support from health workers in Nigeria. Similar findings were also reported in Botswana that supervision of primary and informal caregivers was best provided by trained nurses and social workers (Ama, 2011). He further observed that supervision was an important component of CHBC programme yet it was lacking.

In a recent study done by Akintola, Hlengwa and Dageid (2013), findings indicated that volunteers had moderate to high level stress which is caused by work overload and lack of support. They concluded that stress impacts the volunteers negatively in terms of their well-being and job performance. However, all study participants were women and therefore the results lacked experiences of male volunteer caregivers. In the same study, lack of training came out as a stressor to volunteers. Held and Brann (2007) did a study to explore HIV/AIDS volunteers' stressors and desire for support showed that volunteers expressed the need for training programs where they would learn from each other. In another study which was done in South Africa, caregivers commonly expressed the need for personal development where they wanted to further their education (Akintola, 2005). The findings on training for volunteers show that its absence can demotivate the volunteers.

Another challenge that volunteers faced was poverty at patients' homes. An ethnographic study was done in South Africa explored the challenges experienced by volunteer caregivers of people living with HIV/AIDS and strategies employed in

coping with these challenges. Findings showed that poverty was a serious issue which was raised by all study participants (Akintola, 2008). In the study, the author reported that volunteers assisted those who could not feed themselves or paid school fees for their children as an obligation felt from being close to the patient's family.

Conclusion

The available literature illustrates that CHBC volunteers far and wide recognize the importance of providing home care to HIV and AIDS patients. Majority of the carers were women. The studies that have been reviewed showed that the CHBC volunteers carried almost similar burden of care which included provision of basic nursing care, doing household chore and making referrals among others. Motivating factors were also common amongst the countries. In Nigeria and South Africa, studies have revealed that volunteers also looked forward to gaining experience for paying jobs. On the challenges, the trend was similar. Their work load was enormous and at the same time lacked adequate support from local clinics and the community. However, financial reward was the least motivator. Studies that have looked at the experiences of volunteers have rarely been done in Malawi. The few studies done had findings on just some of the aspects of CHBC volunteer experiences such as motivation, roles and challenges. Other areas like the support system have not been fully explored. It was the aim of this study to unveil the experiences of CHBC volunteers in HIV and AIDS care in Malawi.

CHAPTER 3

Research design and Methodology

Introduction

This section will provide details of the research design and methods used to undertake the study including trustworthiness. A qualitative descriptive approach was used in this study. The study was carried out in the philosophical foundation of naturalistic inquiry. In naturalistic inquiry, the participant is studied in his natural state, in a manner as free as possible (Sandelowski, 2010).

Study setting

The study was carried out in Dowa District, in the central region of Malawi. Dowa borders with Kasungu to the north, Ntchisi to the North East, Salima to the East and Lilongwe to the South. The whole district covers a catchment area of 3,041sq.kilometers and has a total population of 594, 150 giving a population density of 195 per sq. kilometres (National Statistics Office [NSO] & ICF Macro, 2011). The district was chosen because it was among the districts with established CHBC services for years and rich data was therefore expected.

Dowa district had 3 NGOs, 12 FBOs and 68 CBOs which were offering CHBC services at the time of the study. Three CHBC organisations with highest number of patients were chosen to participate in the study namely; Nyundo, Madanka and Kawere CBOs.

Nyundo CBO

The organisation is located in group village headman Nyundo, in Sub-Traditional Authority Msakambewa in the eastern part of Dowa District. At the time of the study, the local organisation had 35 members, 21 women and 14 men and was

looking after 10 patients. The organisation provides CHBC services to 8 villages. The CBO is near Dzaleka health centre. Five participants were interviewed.

Madanka CBO

The organisation was established in 2005 and is located in group village headman Nyongo in Traditional Authority Chiwere in the eastern part of Dowa District. Its offices are located at Mauadzinja village between Thonje School and Banga School, near Church of Christ. CHBC services from the organisation cover 16 villages. At the time of the study, there were 22 members in the group with 18 females and 6 males looking after 17 patients and only one was bedridden at the time. The nearest health facility is Thonje Health Centre. Four participants were interviewed from the organisation.

Kawere CBO

Kawere local organisation is located along M1 road at Kawere village in Sub Traditional Authority Mponela in the western part of Dowa District. It covers 12 villages with CHBC services serving 30 clients and patients at that time. At the time of the study, there were 13 females and 7 males as members of the group. Mponela rural hospital is close to the catchment area of Kawere CBO. A total of six participants were interviewed from the organisation.

Population

The study population was CHBC volunteers working in the district. Dowa district had a total number of 6528 CHBC volunteers at the time of the study.

Sampling and sample size

The study used non-probability sampling whose aim is not to generalize but to uncover truths about a phenomena (Gerrish & Lacey, 2010). Participants in the

study were purposively sampled. A total of fifteen participants were interviewed. Recruitment process involved management of CBOs and HSAs who gave information about the study to CHBC volunteers and those who were willing were referred to the researcher for details of the research as contained in the information sheet for participants.

Inclusion criteria

Participants in the study were those that were from the selected three CBOs. Only participants with work experience of one year or more were included. Their participation in the study was also dependent on expression of willingness to share their experience in HIV and AIDS care. In addition, those who were able to communicate effectively in *Chichewa* were considered. Participation was also based on their availability.

Exclusion criteria

All CHBC volunteers with less than one year experience and not working in the selected organisations were not part of the study. Those participants who expressed unwillingness to participate in the study were not included.

Trustworthiness

Lincoln & Guba (1985) described the scientific rigor criteria framework which increases the trustworthiness of the study. The framework suggested four criteria for developing the trustworthiness of a qualitative inquiry which involves establishing the credibility, dependability, confirmability and transferability of the findings.

Credibility

Credibility refers to confidence in the truth of the data and their interpretations (Polit & Beck, 2012). In this study, the researcher only engaged participants as per

inclusion criteria. This is because unwilling participants cannot express themselves fully hence can compromise richness of the data. In addition, the researcher used probes during the in-depth interview in order to encourage participants to give detailed information regarding experience in provision of care. In order to enhance participant understanding of the research questions, the questions were well elaborated to participants before they could give responses.

Transcription was done by the researcher alone to maintain consistency in capturing of information. Furthermore, credibility of the findings were achieved by doing thorough checks of the transcripts to rule out any obvious mistakes and constantly making sure that the code definitions are maintained (Creswell, 2009). In the earlier plans, data accuracy was to be done through member checking. However, the checks were done but differently. Data were being collected in the rainy season hence the researcher was afraid that she might meet bad roads by the time transcription was ready to perform this task. To this effect, member checks were done at the end of the interview. The researcher went through the field notes with the participants to verify the accounts.

Dependability

In this study, in order to show that the findings are consistent and can be repeated, a detailed step by step process of everything that were undertaken in the study (research methods, data collection methods and analysis) have been included in the report.

Confirmability

Polit and Beck (2012) defines confirmability as the potential for congruence between and among people about the accuracy, relevance or meaning of data. In this study, confirmability was achieved by recording all the words as spoken by both the

participants and researcher during in-depth interview in order to differentiate participant's views from that of the interviewer's views. Furthermore, during in-depth interviews, the interviewer acted as an active listener and facilitator. This allowed participants to fully give detailed information regarding their experience in provision of care to HIV and AIDS patients.

Transferability

Transferability shows that the findings have applicability in other settings or groups (Polit & Beck, 2012). In order to ensure transferability of the study, the written report provided a detailed description of the study findings in order to allow other individuals to assess the extent to which the findings are transferable to their own situation. The study findings have provided some useful insights regarding the experiences of CHBC volunteers in HIV and AIDS care. In this regard, individuals shall find these results meaningful and applicable in their contexts.

Ethical Issues

The proposal was submitted to the research and ethics committee at the College of Medicine for approval of the study in Malawi (Appendix 11). After COMREC approved the study, permission was then sought from the District Health Officer to conduct the study in Dowa (Appendix 9) and from the selected organisations. Information about the study was given to the participants (Appendix 1 and 2.). The participants were informed about the following: purpose of the study, procedures, risks and benefits, confidentiality and contact information of the people doing the study. Participation was voluntary and all participating CHBC volunteers gave a written consent before commencement of the interview (Appendix 3 and 4).

Participants were also informed of their right to refuse or withdraw and that no penalty would be granted upon such a decision. Participants were assured of

anonymity by use of code numbers instead of names on the scripts and tapes. Audio privacy was maintained during interview sessions by conducting the interview sessions in a place where traffic of people was not allowed. All interview information on hard copies were kept in a lockable drawer accessible to the researcher alone while the electronic information was kept in the researcher's personal lap-top with a password. All the study information would be archived at KCN library immediately at the end of the study. The researcher was prepared to counsel participants who would require the service because of psychological stresses arising from participation in the study. However, no counselling sessions were done because no stresses arose as a result of the study.

Data Collection

Data collection instrument

The researcher developed a semi-structured interview guide with open-ended questions in English and translated into *Chichewa* (Appendix 5 and 6). A pre-test was conducted in order to test the interview guide. The pre-test was conducted with two Light House volunteers (one male and one female) coming from different parts of Lilongwe city. The pilot test assisted the researcher in determining flaws, limitations, or other weaknesses within the interview guide. It was found that the interviews took between 35- 45 minutes. One guiding question on the roles of CHBC volunteers was completely restructured in the *Chichewa* version because the first version was misinterpreted by the participants. The exercise therefore allowed refinement of research questions.

Data collection process

Individual in-depth interviews were conducted within the CBO premises for two CBOs. In the third CBO, interviews were conducted in a nearby unfinished house structure because the roof of the CBO office had just been blown off by heavy rains. Creswell (2007) indicates that it might be easier to conduct the interviews with participants in a comfortable environment where the participants do not feel restricted or uncomfortable to share information. Furthermore, when interviews are done in the field, it maintains the natural settings where phenomena occur (Streubert & Carpenter, 2011). The researcher conducted the interviews herself. All the interview sessions were done in local language of *Chichewa* in which all participants were able to express themselves freely.

A digital recorder was used to record the narratives by the participants after gaining consent. Field notes were taken alongside recording. Probes and prompts were made wherever necessary in order to get detailed information. This open-endedness allowed the participants to contribute as much detailed information as they desired and it also allowed the researcher to ask probing questions as a means of follow-up (Turner, III, 2010). The average duration for each interview was approximately 60 minutes. Data were collected in the months of November, 2014 and March 2015. The gap in between was created by rains which made the roads leading to CBOs difficult to pass. All recordings were transferred into a personal laptop.

Three research assistants were engaged to assist in taking down field notes on participant responses and behaviour during the interview session. Each interview site had a different research assistant. The research assistant was taken from the health facility that was near the CBO for easy logistics since funds for the study were limited. One of the research assistants was a community health nurse with a vast experience of community health programs and she also happened to be a trainer and

supervisor in CHBC. The other two research assistants were HSA supervisors who were conversant with CHBC issues. An orientation was conducted on the task of data collection before commencement of the interview sessions. In the last three interviews, all research assistants were engaged as a result few field notes were taken by the researcher herself because much attention was put on listening and probing.

Data Analysis

In this study, data was analyzed by thematic aided by a framework approach according to Ritchie and Lewis (2003). The approach is one of the analytical frameworks that are gaining popularity in data management and analysis for qualitative studies. The framework approach is similar to thematic analysis in the initial stages of theme identification (Smith & Firth, 2011). All voices were recorded by a digital recorder and transferred into the researcher's laptop. Data were transcribed verbatim. The analysis process involved the following steps: (1) Data management- the researcher got familiarized with the data through repetitive reading. Identification of initial themes or categories was done. The data were assigned in the coding matrix. (2) Descriptive accounts- In this stage, a summary and synthesis of the range and diversity of the coded data were done by refining initial themes and categories. The researcher also identified association between them. (3) Explanatory accounts- The stage involved the development of patterns within concepts and themes. Reflection on the original data and analytical stages was done in order to ensure that participant accounts were accurately presented and possible misinterpretation was reduced. Finally, the researcher worked on finding meaning of the concepts and themes which were explained while seeking wider application of the concepts and themes.

Among the advantages of using the framework approach is the fact that there is transparency in the way the researcher interprets participant experiences (Smith & Firth, 2011). Furthermore, the interconnected stages in the framework approach explicitly describe the processes that guide the systematic analysis of data from initial management through to the development of descriptive to explanatory accounts. The authors further assert that a framework to guide the stages of the data analysis has the potential to assist in developing the skills required to undertake robust qualitative data analysis for the novice researcher.

CHAPTER 4

Findings

Introduction

This section has presented the research findings. The study being qualitative in nature, in-depth interviews were utilized to collect data and were guided by a semi-structured interview guide which the researcher developed. To reveal the lived experiences, the interview guide contained a set of open-ended questions examining the participants' volunteerism experiences in HIV and AIDS care at home. These included, what motivated them to be a CHBC volunteers, experiences on the roles that they undertake were also explored. In addition, participants were also asked to describe the support that they received in their work. Furthermore, challenges that the participants experienced were also explored and ways of overcoming them. The interview sessions were characterized by a lot of probing for the researcher to fully understand the experiences of the CHBC volunteers thereby meeting the objectives of the study.

Study Findings

The findings are represented in two sections with the first part covering the demographic characteristics of the participants and the last part covering the narrative results within the emerging themes.

PART A

Demographic characteristics

Demographic features that have been presented are: age, sex, marital status, education level, tribe, occupation and religion. It also further outlines the years of

voluntary service in CHBC among the volunteers and status of formal training in CHBC. Descriptive statistics were used to analyse the demographic characteristics of the participants. Demographic data have been presented in a table. A total of fifteen CHBC volunteers were interviewed (n =15). The following were the results:

Table 4.1: Demographic Characteristics

Characteristic	**Category**	**Total (n)**
Sex	Males	5
	Females	10
Age	25-40	10
	>40	5
Marital status	Married	13
	Divorced	1
	Widowed	1
Tribe	Chewa	13
	Mang'anja	1
	Ngoni	1
Education	Secondary	3
	Primary	10
	Adult literacy	1
	None	1
Occupation	Farming	13
	Business	1
	Apprenticeship	1
Religion	Christianity	15
Formal CHBC training	Trained	9
	Not trained	6

PART B: Narrative findings

The following five thematic areas namely: motivational feelings reduced patient workload, helplessness, frustration and support emerged. Presentation of findings has also included the original descriptions from participants. This has been done to support the themes that were identified.

Table 4.2: Table of themes

THEME	**SUB-THEMES**
Motivational feelings	Compassionate feelings Fulfilling obligations Satisfaction
Reduced patient workload	
Helplessness	Lack of food and other items in the patient's home Socioeconomic burden
Frustration	Lack of resources Discouraging remarks by the community CBO management problems Rejection
Support	Supportive community Reduced healthcare workers' support

Table 4.3 shows the key of symbols that have been used in the text and their meaning:

Table 4.3: Key of symbols

Symbol	Meaning
(....)	Pause
(+)	Laughter by participant
(++)	Laughter by both participant and interviewer

Theme 1: Motivational feelings

CHBC volunteers were motivated from a background of different reasons. Participants were asked what motivated them to join CHBC volunteer work and what attracted them to continue with the work. The study revealed that CHBC volunteers were motivated by their feelings of compassion for the suffering, obligation of social and religious background, and satisfaction with the care and health outcomes of their patients.

Compassion for the suffering

Majority of the volunteers expressed that they were motivated by seeing people who were suffering in the community. They had concern for patients and orphans because they lacked proper support, some were dying and orphans were also suffering. Below are some direct quotes from participants which showed feelings of compassion: “We had many patients and the number of those suffering from chronic diseases kept on increasing. As a result, I made a decision to be among those who take care of the sick in the village.” (Participant 6)

In the same way, Participant 3 had these feelings, "the people who were suffering from chronic illnesses lacked proper support. Things were being done haphazardly because we lacked knowledge. The organisation was formed with the aim of helping the suffering people".

Fulfilling obligations

Participants reported that they felt obliged to continue with the work of CHBC volunteering because it was their own community; the suffering people were their own relatives and friends. In addition, participants felt that it was a religious obligation to be involved in CHBC work. The following account illustrates the social obligation.

> We are still being encouraged to continue working because the suffering people are our friends. It doesn't matter that they were found with such a chronic disease, but the fact remains that they are people like us. So we continue to chat with them to allay their anxiety and we see it as something not difficult to do. (Participant 5)

Another participant expressed it in this way:

> We are still courageous because among the orphans and those that are sick are our relatives and friends. We are the people that help them with some work in the household as a result things go on smoothly and this encourages us. (Participant 3)

Religious obligation was also evident where by the participants felt that they were doing God's work. "Helping others made me very happy because it is something that I was looking for. The bible teaches that we should be visiting the sick."(Participant 7)

Satisfaction

The study revealed that few CHBC volunteers were still kept in voluntary work because they felt satisfied with the results of their work. Hence they were inspired to continue with the work. One participant said:

> I am encouraged to work hard because of the results of my work. Firstly, as earlier on said, HIV related deaths were common in our community as they occurred every month. But when we started this work, we saw things improving little by little up until now. (Participant 13)

Another participant added how she felt satisfied and said:

> We have saved many people's lives and this encourages me. Unlike in the past, most of them died because of lacking such kind of help. I am also encouraged by the fact that people are now able to understand such that they come in the open to tell us about their problems. (Participant 10)

Again, participants reiterated that they continued volunteering with the satisfaction of getting the same support in future when they got sick. They looked forward to receiving care from fellow volunteers because of their past involvement in CHBC work. "I am encouraged because I might get sick in the future and my friends will take care of me" (Participant 12). Another participant shared the same views to say, "We work hard for us to keep our promise to God. I might get sick in the future and I do not want to lack carers."(Participant 10)

Theme 2: Reduced patient workload

The study demonstrated that the workload for the volunteers was light because on average a CHBC volunteer looked after two patients. Most of those patients had

HIV and AIDS and were on ART. Out of the patients that the participants were taking care of, very few patients had other conditions like stroke, asthma and general body pains.

One of the participants said, "We have ten patients only under our CHBC programme and we still make patient visits. We discharged other patients who got better and are able to work" (Participant 2). When asked on the number of patients that she was specifically looking after, she said, "I personally visit one patient. She is suffering from AIDS but she is now better. She is able to farm in her garden although she complains of protruding upper back. She said that possibly her body is not tolerating to the new ARVs."

Another participant also expressed reduced number of CHBC patients in this way:

> All the patients that we have been caring for in the past were 35 initially. We could discharge the patients according to how we were taught that when a patient seems to be strong and fine can be discharged. Then we could take those who are bed ridden and now we have about 10 patients that we work with. (Participant 2)

The care that was being offered by the CHBC volunteers included promotion of body hygiene and chatting with the patients. Sometimes they supported the spiritual needs, gave health education and counseling to patients. Additionally, they fed patients and performed wound care.

It was evident from the findings that the reduced workload was also contributed by the lack of resources. Participant 1 narrated that, "We just visit them to see how they are doing and also give them some hope and reassurance. Even the pattern of the visits is not the same with the time we had the resources."

She continued to say that “The resources that we use now are those that are available at their homes, just for household chores. Another participant also reiterated how lack of drugs has affected his workload:

> Anything that is found in the CHBC kit helps us to provide the care to the patients. The only available drugs are panadol and aspirin which we get from the hospital while the other supplies are not available. It reached a time when these drugs too were not available at the hospital. This was a blow to us and that made us stop doing some of the things on our patients. (Participant1)

Theme 3: Helplessness

Lack of food and other items in the patient’s home

Participants felt helpless with some of the situations that they met. They experienced lack of food in the patient’s home. One participant narrated how she felt helpless when the said the following:

> When we visit our patients, they complain to us specifically on issues of food. This is a problem more especially during this time of the year. The patients even verbalize that without food, they fear of dying from hunger. We just reassure them not to complain too much about that. (Participant 4)

Another participant described other resources which lacked in the patient home. She said:

> Another problem is that our patients sleep in undesirable places which are dirty and the beddings are not enough. This really worries us because they are supposed to sleep at a good place which is well taken care of. They lack many things but our support is limited. (Participant 7)

Socioeconomic burden

The study results showed that CHBC volunteers were supporting their patients with finances and other needs at a small scale because of lacking food and other items. Participants reported that they bought items for their patients and others either gave out small amounts of money or worked in the patient's garden. Participant 2 said, "If we have some little money, we buy soap and give it to the patient. We sometimes give vegetables and maize flour to the patients. One participant among those who expressed that they offer food to their patients said: "When there is no food in the patient's home, we give them what we can afford." (Participant 11)

Theme 4: Frustration

Lack of resources

Participants bemoaned reduced support and more common was lack of drugs and transport means for patients and volunteers.

The following excerpt illustrated the problem of lack of resources:

> We lack HBC kit like aprons, drug boxes, and also the other problem is that drugs were finished long time ago. Most of our patients do complain that we stopped giving them drugs. When we go to the hospital, drugs are not available either, that is the major challenge now. (Participant 6)

The same participant continued to narrate how lack of transport frustrated them:

> We need an ambulance bicycle and other bicycles. These can help so much because we move around 16 villages. These are long distances and it becomes difficult to walk. We cannot continue hiring bicycles because it is very expensive. The money that we could use for hiring could benefit our patients. (Participant 6)

Similarly, another participant complained on the lack of resources, "The organisation that used to support us stopped therefore, we lack resources which we cannot afford to have on our own. It is difficult to reach out to patients when we don't have enough resources." (Participant 1)

The results indicated that CHBC volunteers were at times buying the drugs for their patients commonly panadol and aspirin. "At our organisation we do not even have money to buy panadol for pain relief. They go to hospital if they can manage. Sometimes we give them K100 to buy panadol for pain relief which is about 5 strips." (Participant 2)

Apart from hiring transport for patient referrals, lack of transport disturbed the activities of the participants' homes. "When there is a long distance to where the patient is, we usually cancel gardening on that day or we may go early and come back early so that we are not burnt in the sun" (Participant 4) . One participant even said that lack of transport affected their family life because they returned home late

after patient visits. This was due to long distances that they covered to reach patients. This attracted queries from husbands who wondered what caused the lateness. She expressed it in this way: "It will be good to be given bicycles because we visit faraway places hence coming back late when dark has fallen. Some married men do not easily understand this and they ask us what we have been doing (++)."(Participant 9)

Discouraging remarks by community members

Some community members frustrated the CHBC volunteers by their discouraging remarks towards them.

> People talk a lot about us like not being trained and working without gains. We tell them that this is God's work and we did not start it to benefit financially or to go for training (…..) but we cannot tell; the training might come. We are not discouraged by what the people say otherwise you would not have met us here. We know if we stop many of our patients will have premature deaths. (Participant 9)

CBO management problems

Problems that occur in the management of the CBO where the CHBC volunteers belonged also caused frustration in them.

> People initiate things but when it comes to implementation phase, different people are engaged. For example, people who work hard may not be considered for training when it comes. You may find that they take people who are not well known. This is very disappointing. (Participant 11)

Problems of lack of finances in the CBO were also revealed by the participants. One of the participants said:

> (+) Some of the problems include weakness of the group by failing to perform its functions because of money. When money is not available it means our group is in trouble. The fact is that we are failing to end financial problems. (Participant 1)

Rejection

CHBC volunteers reported feelings of being rejected more especially in the early days of their volunteer work. One participant had this to say: 'People who were group members were labelled as HIV infected as a result some patients banned our visits in their homes including counselling sessions on hygiene and self-independence.' (Participant 13)

Another participant expressed it in this way:

> We were also having problems to register patients in the beginning. They were asking, 'who told you that I have AIDS?' Sometimes their children would stand by us trying to convince their parents who are infected by the disease that we are home based care people. Some were understanding and others not. We never pressurised them. (Participant 2)

Theme 5: Support

Supportive community

Participants expressed that they got most support from patient's family members, community members and their CBO in the care of patients.

The following narration illustrated support from family members:

> The guardians help us a lot like reminding patients to take drugs because on their own they can forget. They do remind the patient the dose and how to take the drugs. They also remind the patient to pray before going to bed and in the morning all based on our encouragement. (Participant 8)

The general community members were also in support of the CHBC programme in this study out of solidarity. One of the participants expressed it as follows: “I see that we collaborate very well with the community. Even other people in the village they don’t just sit back and watch. Sometimes I had observed that they brought things for the patients.” (Participant 7)

CBOs to where the participants belonged also supported the CHBC volunteers in the care of the patients. CBO support was expressed in the following way by one of the participants: “Our organization helps us because we conduct meetings and plan for patient visits. The meeting alone encourages us to allocate visiting teams to patients and give each other deadlines for visiting patients. We see that the organization supports us through these reminders. In the past we were able to farm and get a little something like soap and give the patients. (Participant 3)

The study showed that some of the participants expressed that they got support from the patients. One of the participants said:

> Patients adhere to what a volunteer or his guardians tell him by taking his medication as prescribed. If he is bedridden, he reminds the guardian that it is time to have his medication. Sometimes he can also ask for church elders to come and give him spiritual care. If guardians have forgotten to take care of his beddings, he takes the responsibility to tell his guardian to have them changed. (Participant 13)

Reduced health care workers' support

Participants in the study acknowledged HSA support in CHBC and one participant said:

> The HSA provides us with gloves when we run out of gloves. They also encourage us to remind patients to go to the hospital on the appointment dates. Because most of the patients forget, even the guardian forgets sometimes. (Participant 4)

In the study, several participants said that nurses and other health workers were not supporting the CHBC services. One of them said, "To be honest, nurses have never assisted us. Nurses' focus is on child bearing aged women and pregnant women and not on home based care" (Participant 15). Further, an expression of lack of support was given by another participant as follows: "The support we have in the meantime is just within ourselves because those who were supervising us stopped and we don't even know where to submit our reports"
(Participant 10)

Conclusion

This chapter has presented the study findings with narratives as presented by the participants. Findings indicated that CHBC volunteers are mostly motivated by feelings of compassion for the suffering, social obligation and religious obligation. It has further revealed that workload for the CHBC volunteers had reduced and commonly the CHBC volunteers were doing household chores and some basic nursing care roles. The study has also demonstrated that CHBC volunteers got more support from family members, HSAs, community members and CBOs and less support from nurses and other healthcare workers. Finally, the study has revealed that CHBC volunteers were helpless and frustrated by lack of resources, discouraging

remarks from the community and CBO management problems. The next chapter has made a discussion of the findings.

CHAPTER 5

Discussion

Introduction

The goal of this study was to explore and describe the experiences of CHBC volunteers in HIV and AIDS care. In this chapter, a synthesis and interpretation of the emerging themes was made. Relationship of the themes thus similarities and variations with other research were elaborated. The discussion falls along the identified themes which are: motivational feelings, reduced patient workload, helplessness, frustration and support.

Demographic characteristics of participants

The sex distribution showed that the majority of the participants were females. This is in consistent with what other research studies found that the burden of care for HIV and AIDS patients rests heavily on women CHBC volunteers (Akintola, 2004). Most of the study participants were middle aged which is a common finding that few young people engage in CHBC volunteer work. Similar findings on age were reported in Zimbabwe and South Africa (Akintola, 2010b; Osawa et al., 2010).

The findings also showed that the majority of the participants had attained primary education hence could read and write the local language. These qualities are necessary in CHBC care provision because CHBC providers have a role to keep patients' records on the care provided and also provide monthly reports to their immediate supervisors (Ministry of Health, 2011). Almost all the participants were Chewa by tribe which is the largest ethnic group in the central region of Malawi and Dowa district in particular. The distribution status was good because the CHBC

providers could be able to understand the culture of their patients who mostly would be Chewa people. Findings showed that most of the study participants had received formal training in CHBC. CHBC volunteer trainings contribute to effective provision of care to the patients (Ministry of Health, 2011). The fact that majority of the participants were subsistence farmers explains the food contributions which they made to patients who lacked food. The economy of Malawi is based primarily on agriculture, which accounts for 30 percent of the gross domestic product (NSO & ICF Macro, 2011).

Motivational feelings

This study has shown that CHBC volunteers were mostly motivated by feelings of compassion for people who are suffering in the community. Compassionate feelings rose from seeing suffering people including orphans who some of them lacked proper support. The study results were similar to the studies conducted in South Africa where compassionate feelings for helpless situation of people in the community motivated volunteers to join the work (Akintola, 2008; Akintola, 2010a; Marincowitz et al., 2004) . Similarly, another study done in Zimbabwe also echoed the same results as it was observed that volunteers had empathy which derived from witnessing the suffering from AIDS (Rödlach, 2009). UNAIDS (2000) stated that simple compassion for others who are suffering is a common motivation for volunteering.

Study results indicated that religious obligation was another motivation drive for volunteers to join HIV and AIDS work. The results coincided with the results of the studies looking at motivating factors which found that volunteers are driven by religious obligations and values to take care of the sick (Akintola, 2010a; Rödlach, 2009) . The findings are also in consistent with study results from Blantyre, Malawi

where religious values compelled community care givers to volunteer themselves for the work (Mkandawire & Muula, 2005). This implies that in Malawi and across the border, religious values are common as initial and ongoing motivators for the CHBC volunteers.

This study demonstrated that CHBC volunteers were also motivated by the social ties that they had. The relationships they had with friends and relatives were important to them hence offering them care. Marincowitz et al. (2004) reported social drives in South Africa where assisting own people made it easy for home-based care volunteers to continue with the work. However, other studies have shown that relationship ties did not matter. Family members have neglected sick relatives as reported in South Africa (Mashau & Davhana-Maselesele, 2009; Motswasele & Peu, 2008).

Satisfaction resulting from health outcomes of their patients was another motivator in this study. The participants reported that they kept on working because they had seen many lives being saved through their work. In South Africa, similar reports were made from studies which indicated that the fact that patients got better with volunteers support was an important motivator (Marincowitz et al., 2004; Primo, 2007).

Findings demonstrated that CHBC volunteers were mostly motivated for the good of their patients than for personal gains. On the other hand, very few participants reported the need for monetary incentive in this study which is similar to what Mkandawire and Muula recorded in their study. They found that few community care givers expressed the need for monetary rewards (Mkandawire & Muula, 2005). Other studies done in Nigeria and Malawi have indicated that monetary rewards are actually motivators for few caregivers (Adebimpe et al., 2013; Munthali, 2009). It must be noted that in some parts of the world, the voluntary work in HIV and AIDS

care attract small remunerations. It is in this view that Primo (2007) indicated that one of the needs for caregivers is an increase in stipend. However, the need for monetary incentive has been debated upon. Rödlach (2009) in his study found that the small remunerations that the care facilitators received contributed to the welfare of their families which justifies the need for monetary rewards. While another argument by Kironde & Bajunirwe (2002) stated that giving rewards to people who have high interest and already enjoy doing the work may be counterproductive.

The motivators in this study have good implications in terms of continuity of volunteer services because if volunteers look forward to more personal gains then it could influence drop-outs. This argument is supported by the many years that the study participants had served in CHBC work.

Roles of CHBC volunteers

In this study, CHBC volunteers were mostly performing household chores and basic nursing care roles. Participants reported that they performed household chores like cleaning the environment, fetching firewood, drawing water, repairing roofing and constructing bathroom shelters. Likewise, a study done in Blantyre, Malawi by Mkandawire and Muula (2005) found that community care givers visited patients and assisted with household chores such as sweeping, bathing the patients and cooking. Basic nursing care activities that this study had revealed were: giving health education, bathing of patients and supporting with spiritual needs which were reported by few participants. Masanjala and Kajumi (2013) also reported similar findings that there is revolution of caregiver roles from basic nursing care to broader livelihood, nutritional and psychosocial support including monitoring patient adherence on ART.

Studies done in Malawi and South Africa found that inclusive in the basic nursing care package that was offered was provision of physical care or treatment of

minor ailments for the patients (Njobvuyalema, 2011; Osawa et al., 2010; Primo, 2007). In this study, only one participant reported having offered physical care on a patient. Possibly, this could be as a result of having more people receiving the life-saving antiretroviral therapy (UNAIDS, 2013) hence reduced opportunistic infections. This might have affected reduction of volunteer workload as most patients were no longer bedridden. On the other hand CHBC kits were empty as reported in the study hence CHBC volunteers could probably not treat minor ailments which they came across with.

In addition to performing household chores and offering basic nursing care, the study found that CHBC volunteers offered socio-economic support to their patients/clients for example, buying items like soap and food and farming in the patients' garden. Past research studies are consistent with these results. Studies in Malawi and South Africa found that volunteers brought food items, money and offered labour to the patients' farms (Akintola, 2004; Mkandawire & Muula, 2005; Munthali, 2009). The finding from this study showed that the contributions that the volunteers made towards the welfare of their patients instilled some fear even before joining CHBC groups. The fear came in possibly because CHBC volunteers are commonly of low economic status and making contributions towards patient's welfare is another burden. In addition, the food contributions may be based on quantity and not quality in terms of nutrition components.

Support system of CHBC volunteers

The study found that all study participants recognized support from family members in delivery of patient care. The study further showed that family members mostly assisted in household chores which was also a common activity done by volunteers in the study.

These findings support a study by Pindani (2010) who found that relatives provide the most support to patients among others. However, these results are contrary to the findings from South Africa where family members neglected patients and reportedly gave poor support to patients (Mashau & Davhana-Maselesele, 2009; Motswasele & Peu,2008) . The latter attributed the poor support to lack of knowledge on the part of the family members which greatly impacted on the care of patients.

HSAs are the extension workers in the Malawi healthcare systems who work directly with the communities, community care providers and village health committees. The study showed that all CHBC volunteers acknowledged support from HSAs. The support was in the form of resource provision, encouragements, patient's home visits, attending volunteer meetings and facilitating prompt treatment of referred patients at the health facilities. According to Ministry of Health (2011), HSAs act as a link between the community and the health care facilities. The fact that the HSAs work directly with the community may justify the findings on their support to the CHBC groups.

Apart from getting support from the family members, the study revealed that the general community also provided care to patients in support of CHBC. They assisted with referral of patients, reported patient's condition, contributed things to patients and worked at patients' homes. In the study, the activities done by the general community in the patient's home were almost similar to what CHBC volunteers did. The difference was the pattern at which the services were offered where they were offered frequently by the volunteers. In addition, the community mobilised finances and assisted with activities at CBO offices. Local leaders also participated by mobilising people to work on CHBC activities. Studies done in South Africa and Malawi had similar findings (Akintola, 2010b; Motswasele & Peu, 2008; Munthali, 2009). The researchers found that the community members acted like caregivers out

of pity. They also assisted in bathing patients and provided food and even gave money to patients.

In contrast, Mkandawire and Muula (2005) in their study found that the communities were not supporting the volunteers with materials towards care of patients because it was not actively sought. Ministry of Health has in the recent years trained community extension health workers (HSAs) in community mobilization for CHBC and this could be one of reasons for the current finding on community support. It therefore implies that the communities are in support of the CHBC services and if properly mobilised, they can help to sustain the CHBC services.

Majority of the CHBC volunteers in this study recognized the support from the CBOs, the organisations to which they belonged. The support came in the form of resource provision, conducting meetings and training of its members. On the other hand, a smaller group which felt no support from the CBOs bemoaned that the bigger organizations stopped supporting them which affected the CBO support. In a study done in Kenya, observations were made that managerial and programmatic support from NGOs was not provided adequately (Takasugi & Lee, 2012) . Another Malawian study concurs with this finding as it found that most CHBC groups observed the fact that external support to the CHBC groups was irregular in other cases declining (Munthali, 2009). The existence of the AIDS pandemic saw a lot of local organisations mushrooming to work on the impact that AIDS brought into the society. In the recent years, there has been little NAC support to the organisations as observed in Thyolo, Malawi (Njobvuyalema, 2011). The possible reason for the dwindled support could be donor fatigue resulting from the global economic crisis.

The study findings showed that some CHBC volunteers acknowledged that CHBC patients took some responsibilities to support care. Patients were being open to volunteers, followed advice and appreciated the care rendered by CHBC volunteers.

The mentioned support by patients demonstrated that patients to some extent were responsible for their own care. According to the patient bill of rights and responsibilities; patients have the responsibility to provide complete and accurate information about their health. The results are similar to the studies done in South Africa which reported that patients appreciated the work done by volunteers and even confessed that they got better with it (Marincowitz et al., 2004; Thabethe, 2011). The study reports further indicated that this acted as a very important motivator for them to continue with the work.

The study findings also showed that the participants felt that nurses and other health workers did not support them. It further revealed that nurses were engaged in reproductive health activities unlike CHBC support in the community. This finding points to the fact that the DHO was not actively involved in CHBC activities at the time of the study. These findings are similar to the findings from South Africa, Nigeria and Botswana where observations were made that there was poor technical and supervision support to CHBC groups by healthcare personnel (Adebimpe et al., 2013; Ama, 2011; Schneider et al., 2008). However, the finding contradicts the study that was done in Thyolo, Malawi where nurses from the district supervised the work of volunteers at the CBO centres and reviewed patients under Medicines San Frontiers- Belgium project (Njobvuyalema, 2011). Perhaps the nurses in Thyolo were able to supervise and support the CHBC activities because of the presence of the international NGO which was supporting the program. Projects have timelines and the findings may be different when the project phases out.

The common source was therefore coming from the community as per findings. Although the community was commonly assisting the CHBC volunteers in patient care, its support was not well aligned to their needs and preferences. It was

evident from the study that among the healthcare workers, the HSA was the most common source of support.

Challenges of CHBC volunteers

Study participants acknowledged facing problems in their CHBC work. The study showed that the dominant problems facing the CHBC volunteers were lack of resources which caused frustration. The much needed resources included CHBC drugs and transport for patients and volunteers. Studies done in South Africa and Kenya found the same where volunteer caregivers lacked basic resources such as drugs and transport (Mashau & Davhana-Maselesele, 2009; Motswasele & Peu, 2008; Takasugi & Lee, 2012). In addition they also reported that this undermined their work and caused frustration. The results further showed that CHBC volunteers hired bicycles for referral of their patients which posed as a financial burden on the CHBC volunteers. Other local studies have reported the same problem of drug shortage in Thyolo and Blantyre (Mkandawire & Muula, 2005; Njobvuyalema, 2011). This implies that the problem is chronic and common across the region. It is suggested that reasons for the shortage of resources needs to be established.

In addition to lack of drugs and transport, few participants reported that they also lacked training in CHBC. In South Africa, similar findings were also reported where volunteers bemoaned lack of training (Akintola et al., 2013). In this study, some volunteers were found to be untrained for many years. This observation is common in the region, in Nigeria almost half of the respondent in a quantitative study started volunteering without formal training and the same study revealed poor training for volunteers (Adebimpe et al., 2013). The findings are not conforming to the qualities of community care providers who are supposed to be trained for ten days in

CHBC (Ministry of Health, 2011). The situation was perhaps due to the financial constraints that characterized the CHBC groups as per study findings.

In another study which was done in South Africa, caregivers commonly expressed the need for personal development where they wanted to further their education (Akintola, 2005). In contrast, this study found that many of the CHBC volunteers expressed the need for formal trainings in CHBC. The trainings assist in the acquisition of knowledge and skills and motivates CHBC volunteers (Munthali, 2009). According to Ministry of Health (2011) trained CHBC volunteers contribute to effective provision of care to the patients.

Findings from this study also showed that study participants were helpless because they faced poverty in the home of their patients. This was manifested by inadequacy of food items, clothing and beddings. In South Africa, volunteers also reported that poverty was a serious issue on food and other financial needs like school fees (Akintola, 2008; Motswasele & Peu, 2008). The study further indicated that these problems were shouldered by the volunteers through provision of food items and school fees. This showed that food shortage was a common problem in patient's home in the region. Volunteer contributions towards the welfare of patients could therefore scare away some CHBC volunteers from joining the CHBC groups.

In this study, CHBC volunteers were also frustrated by discouragements made by people in the community. Akintola (2005) found the same results in South Africa where friends and neighbours gave discouraging comments to CHBC volunteers. However, the community members supported CHBC services to a great extent as per findings of this study which

In addition to the many problems that were found from the study, the results showed that there were also problems within the CBOs. Lack of finances in the organisations further frustrated CHBC volunteers. The study also showed that the

means of generating income was not sustainable for example individual contributions. Participants expressed the need for NGO support. During the study, it was observed that two of the selected CBOs had at one time received financial support from external organisations. The support which these organisations offered included trainings, CHBC kits and ambulance bicycles and bicycles. This echoes the finding by Munthali (2009) who revealed that the presence of external organizations bring resources to the CHBC groups. However he also observed that the support often causes dependency and opportunism. The study findings showed that none of the CHBC groups had stable financial capacity. They depended on individual contributions and none were engaged in a sustainable IGA. Perhaps CBOs relied more on external organisations for material and financial support. The fact that many of the study participants greatly needed CHBC drugs and transport emphasizes the need for financial stability for the CBOs.

Other local studies found that support to the CBOs had declined and this affected the financial capacities of the CBOs (Munthali, 2009; Njobvuyalema, 2011). In the study it showed that CBO members were active during those times when the CBO had external financial support. This indicated that CBOs have been weakened because of lack of financial support.

Frustrations also arose from favouritism which CBO management exercised during selection of participants for training in CHBC. Similar findings were reported in Kenya where community health workers felt that access to improve their skills was denied because opportunities were dished out selectively (Olang'o, Nyamongo, & Hagaard-Hansen, 2010). In addition they also reported that PLWA accused community health workers of squandering donations brought in their names. This is almost similar to what this study found where PLWA were in conflict with CBO

members who were often attending meetings of which the latter felt those meetings were meant for them.

The fact that participants reported incidences of rejection in the early home visits showed that issues of stigma affects utilization of HIV and AIDS services by the patients. As stated earlier, similar problems have been faced in South Africa, where volunteers experienced poor reception in the patients' homes on the first visits but improved later (Akintola, 2005; Mashau & Davhana-Maselesele, 2009). Another possible reason to this rejection could be poor counselling of patients during registration phase of CHBC patients and clients. This argument is supported by the fact that some untrained volunteers have done the work with no experience in counselling as per findings of this study.

Recommendations

Based on the findings from this study, the following recommendations are being made to CHBC programme planners, DHOs and the community.

CHBC programme planners

For continuity of volunteer work, it is recommended that CHBC volunteers should be motivated. This can be achieved through adequate trainings and psychosocial support. Drug budgets for the district councils should include CBO drug needs to reduce the current problem of drug shortage. It is also recommended that at its review, the CHBC training package should include strategies on how the carer (CHBC volunteer) is introduced to the patient and how CHBC volunteers can successfully enroll patients on the CHBC programme.

District Health Offices

There is need to conduct ongoing mentorship for CHBC volunteers on their roles through HSAs and community health nurses because the study has revealed that basic nursing care was not comprehensive. In addition, information, education and counseling role of CHBC providers should be intensified.

Healthcare workers in the community including nurses should be oriented on their roles as regards to CHBC program. In this era where financial resources are minimal, DHOs should integrate CHBC activities within other community based programs to attain integrated supportive supervision. Awareness on the patients' charter should be done to the patients and the community.

Community level

CHBC volunteers should also engage in other activities within chronic care since workload has reduced for the HIV and AIDS patients. With the increase of non-communicable diseases in low and medium income countries, CHBC volunteers could be engaged in health promotion. Continued trainings in health promotion for such emerging conditions would help to ameliorate the situation. Mentorship program for family members should also be done since research has shown that they are doing most of the care for the patients.

CBOs should reduce donor dependency by considering revamping IGAs that are sustainable like commercial farming. There is need to empower support groups of people living with HIV and AIDS in social and economic capacities. Support group members can be encouraged to own kitchen gardens and keep poultry or livestock in the homes. Multisectoral collaboration among different players in the care and support of PLWA should also be encouraged.

Study limitations and constraints

The choice of the setting under study was based on non-probability sampling which limits the generalization of the findings. In addition, the sample only involved CBOs hence results cannot be generalized for Faith Based Organisations (FBOs) and NGOs within the study setting. However, similar findings may be found. The interview guide was open-ended with the aim of allowing the CHBC volunteers to talk a lot about their experiences however, some responses were short and vague. In order to address the problem, the questions were rephrased to probe more with their meaning maintained.

The presence of HSAs and community health nurse as research assistants might have influenced participant responses on nurses and HSA support to CHBC volunteers.

Conclusion

The study was carried out with the aim of exploring the lived experiences of CHBC volunteers in HIV and AIDS care. Findings have shown that humane factors motivated the CHBC volunteers more than personal factors. The basic nursing care interventions were not comprehensive while findings also showed that workload for CHBC volunteers had reduced. The study findings have shown that CHBC volunteers worked under stressful environment culminating from lack of resources and their common source of support was the community. However, the community level support was not well aligned to their needs and preferences. It is therefore recommended that CBOs should have sustainable IGAs in order to support CHBC services.

Areas for further research

There was inadequate support from nurses and other professional healthcare workers in the study. This therefore calls for another study to explore the experiences of nurses and healthcare workers with CHBC program. Another study should also look at the perception of family caregivers towards HIV and AIDS care of their relatives.

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Appendices

Appendix 1: Information sheet for Participants

STUDY TITLE: EXPLORATION OF EXPERIENCES OF CHBC VOLUNTEERS IN HIV AND AIDS CARE IN DOWA DISTRICT, MALAWI.

Dear Participant,

I am Rosemary Bilesi, a Registered nurse/midwife at Mzuzu Central Hospital, but currently I am pursuing Masters in Community Health Nursing at Kamuzu College of Nursing. I am carrying out a research titled "**Exploration of experiences of CHBC volunteers in HIV/AIDS care in Dowa district"**. I would like to welcome you to this study and at the same time give you information about the study which will assist you in making a decision whether to participate or not. Please ask if there is anything that is not clear or you would like more information. Participation is voluntary.

Purpose of the study

The aim of the study is to explore the experiences of CHBC volunteers in Dowa district. This is for improvement of Community home based care programs.

Procedures

If you consent to participate in the study, you will be interviewed individually, at a private place within the CBO premises. I will ask about the roles of CHBC volunteers, needs and support and the challenges that are faced in the course of the work. The interview will take approximately 45-60 minutes.

Risks and benefits

There are no known risks about your participation. However, should any question make you uncomfortable, you are free to express that discomfort. You may also decide not to respond.

You have the right to refuse to participate or withdraw at any point in this study and you shall not be punished in any way.

As a participant, you will not be able to gain direct personal benefits for participating in the study. However, it may benefit the CHBC program in future. You will not pay anything for participating in the study. During the course of our discussion, I will offer you a drink and a snack.

Confidentiality

Interview session will be tape recorded upon your consent. The information collected from you will be treated in a private and confidential manner. Only code numbers will be used on data collection tools for purposes of identification and the scripts and tapes will be in the custody of the researcher alone and be made available to the research team only. When the research is over, all scripts and tapes will be archived at Kamuzu college of Nursing. The study findings will be disseminated to all CHBC stakeholders for information sharing.

To show that you have agreed to take part in the study, you will be given a consent form to sign or make a thumb print.

For further details regarding this study, you may contact any of the following persons:

Rosemary Bilesi, Kamuzu College of Nursing, Private Bag 1, Lilongwe. Phone: 0992 200 102 or 0881 775 100

Or

The Chairman, College of Medicine Research and Ethics Committee, P/Bag 360, Chichiri, Blantyre 3. Telephone: 01871911

Or

Dr Mercy Pindani, Kamuzu College of Nursing, Private Bag 1, Lilongwe. Phone: 0888896970

Appendix 2: Information sheet for Participants (Chichewa version)

Okondeka mavolontiya ofuna kutenga nawo mbali pa kafukufuku,

Ine ndi Rosemary Bilesi namwino komanso mzamba yemwe akuphunzira za ukadaulo pa sukulu ya ukachenjede ya Kamuzu. Ine ndikupanga kafukufuku ngati njira imodzi yokwaniritsira zolinga za maphunziro anga. Ndakulandirani ndipo ndikufuna kukudziwitsani tsatanetsatane wa kafukufuku ameneyu ndi cholinga choti mupange chisankho chotenga nao mbali kapena ayi. Mutha kufunsa mafunso pamene simukumvetsa. Kutenga mbali pa kafukufukuyu ndi kongodzipereka.

Cholinga cha kafukufuku

Cholinga cha kafukufukuyi ndi kufuna kumva maganizo a anthu odzipereka (mavolontiya) omwe amasamalira anthu omwe anapezeka ndi kachirombo ka HIV komanso odwala matenda a edzi m'boma la Dowa.

Ndondomeko ya kafukufuku

Ndizakufunsani mafunso ngati mutavomereza kutengapo mbali pa kafukufuku ameneyu. Kucheza kwathu kuzachitikira pa malo oduka mphepo. Ndizafunsa mafunso okhuzana ndi nchito zanu pa chisamaliro cha odwala kumudzi, zosowa ndi chithandizo chomwe mumalandira ndi mavuto omwe mumakumana nao. Kucheza kwathu kuzatenga pafupifupi ola limodzi.

Zovuta ndi phindu lochita nawo kafukufukuyu

Palibe kuopsa kulikonse pa kafukufukuyu. Komabe mwina mafunso ena akhonza kukukhumudwitsani. Ngati zitatero, simukukakamizidwa kuyankha. Muli ndi ufulu kutengapo mbali kapena ayi komanso mudzakhala ololedwa kusiyira panjira kafukufukuyu popanda kulandira chilango chili chonse.

Kutenga mbali pa kafukufukuyu ndi kongodzipereka ndipo simudzapezapo cholowa chilichonse. Ngakhale izi zili choncho, maganizo omwe mungapereke akhoza kudzathandizira kupititsa patsogolo ntchito yosamalira odwala kumudzi.

Simuzafunsidwa kuti mulipire ndalama chifukwa chotenga mbali pakafukufukuyu. Mkatikati mwakucheza kwathu, ndidzakupatsani chakumwa choziziritsa kukhosi.

Kusunga chinsisi

Kucheza kwathu kudzajambulidwa ngati mutavomereza. Dzina lanu lidzabisidwa pogwiritsa ntchito ma nambala. Zomwe mudzalankhule zidzasungidwa mwa chinsisi ndipo amene angazione ndi okhao okhuzidwa ndi kafukufuku. Pamathero a zonse zojambulidwa ndi zolembedwa zonse zidzasungidwa kusukulu kwathu. Zopezeka pa kafukufukuyu zidzagawidwa kwa onse otengapo mbali pa chisamaliro cha odwala kumudzi kuti wonse azidziwe.

Pofuna kuonetsa kuti mwavomereza kuchita nao kafukufukuyi, ndidzakupemphani kuti musaine kapena kudinda chala pa chikalata chovomerezera.

Ngati muli ndi mafunso okhudza kafukufukuyi mutha kufunsa kwa anthu awa:

Rosemary Bilesi, Kamuzu College of Nursing, Private Bag 1, Lilongwe. Phone: 0992 200 102 or 0881 775 100

Kapena

The Chairman, College of Medicine Research and Ethics Committee, P/Bag 360, Chichiri, Blantyre 3. Telephone: 01871911

Kapena

Dr Mercy Pindani, Kamuzu College of Nursing, Private Bag 1, Lilongwe. Phone: 0888896970

Appendix 3: Consent Form

Participant ID number…….

I hereby confirm that I have read (or someone has read to me) the detailed information about the nature of the study. I had opportunity to ask questions and my questions were answered to my satisfaction. I understand that my responses will be kept in a confidential manner and that I am free to withdraw at any time if I wish to do so. Therefore, I voluntarily agree to participate in this study.

..... …….

Participant's signature (thumb print) Date

..... ……..

Researcher's signature Date

Appendix 4: Consent form (Chichewa version)

Nambala yachinsisi ya otenga mbali……

Ndikutsimikizira kuti ndawerenga (wina wandiwerengera) tsatanetsatane wa kafukufukuyu. Ndinali ndi mwayi ofunsa mafunso ndipo ndayankhidwa moyenerera. Ndamvetsetsa kuti maganizo anga adzasungidwa mwa chinsisi ndiponso kuti ndikhoza kusiyira panjira kafukufukuyu nthawi iliyonse ngati nditafuna kutero.

……	…….....
Sayini ya otengapo mbali kapena podinda chala	Tsiku
……	……
Sayini ya ochita kafukufuku	Tsiku

Appendix 5: In-depth Interview Guide

STUDY TITLE: EXPLORATION OF EXPERIENCES OF CHBC VOLUNTEERS IN HIV AND AIDS CARE IN DOWA DISTRICT, MALAWI.

Date of interview:

Participant's ID number:

Form No:

Demographic data

Age : 18-25 years □ 25-40 years □ >40 years □

Sex : Male □ Female □

Marital status : Married □ Single □ Widowed □ Separated □ Divorced □

Educational qualifications: None □ Primary □ Secondary □ Tertiary □

Tribe : Chewa □ Ngoni □ Yao □ Tumbuka □ Lomwe □ Sena □ Tonga □

Occupation : Farmer □ Businessman □ Employed □ Piece work □

Religion : Christian □ Muslim □

Trained in CHBC: Yes □ No □

Years of service: 1-2 years □ 2-5 years □ >5 years □

Motivation to caring

How did you become a volunteer caregiver?

What are the things that motivate you to be a CHBC volunteer?

Role of CHBC volunteers

What is your role as a CHBC volunteer in HIV and AIDS care?

Probes:

Number of patients

Their conditions

Services offered

Needs and support

(a) As a CHBC volunteer, what are your needs?

Probes:

Supplies of care

Transport

Training

(b) As a CHBC volunteer, can you describe the support you get in your work?

Probes:

The patient

Family members of the patient

Your organisation

Community

Healthcare workers (HSAs and Community nurses)

Challenges

What challenges do you encounter in your work as a CHBC volunteer?

What do you do to overcome these challenges?

What are your suggestions regarding improving the CHBC program in your area?

-END OF INTERVIEW-

THANKS FOR YOUR PARTICIPATION

Appendix 6: In-depth Interview Guide (Chichewa version)

Tsiku lofunsa mafunso:

Nambala ya chinsisi:

Nambala ya fomu:

Mbiri ya otenga mbali pakafukufuku

Zaka: 18-25 □ 25-40 □ Kupitilira zaka 40 □

Mbiri ya banja: Okwatira/Okwatira □ Mbeta □ Namfedwa □ Abanja anapatukana □ Banja linatha □

Maphunziro : Sindinaphunzire □ Pulaimale □ Sekondale □ Koleji □

Mtundu : Chewa □ Ngoni □ Yao □ Tumbuka □ Lomwe □ Sena □ Tonga □

Ntchito : Ulimi □ Bizinesi □ Yatikiti □ Maganyu □

Chipembedzo : Chikhirisitu □ Chisilamu □

Maphunziro a chisamaliro cha odwala kumudzi: Eya □ Ayi □

Zaka zogwira ntchito yosamala odwala: 1-2 □ 2-5 □ Kupitilira zaka 5 □

Zomwe zimapangitsa anthu kuti azisamalira odwala m'midzi

Kodi ntchito yosamalira odwala m'midzi mongodzipereka munayamba bwanji?

Ndizinthu ziti zomwe zimakupangitsani kukhala osamalira odwala olimbika ndi odzipereka?

Ntchito za osamalira odwala odzipereka

Tafotokozani za ntchito yomwe mumagwira pachisamaliro cha anthu omwe ali ndi kachilombo ka HIV komanso odwala edzi?

Kufufuza mozama

Chiwelengero cha odwala

Mavuto a odwala

Ntchito zomwe zimagwiridwa kwa odwala

Zofunika ndi chithandizo pa ntchito yosamalira odwala kumudzi

(a) Ndi zinthu ziti zomwe zimakuthandizirani kuti mugwire bwino ntchito yosamalira odwala kumudzi?

Kufufuza mozama

Zipangizo zogwirira ntchito

Mayendedwe

Upangiri/ Maphunziro

(b) Kodi mungafotokoze thandizo lomwe mumalandira pa ntchito yanu?

Kufufuza mozama

Kuchokera kwa odwala

Kuchokera kwa abale a munthu odwala

Kuchokera kubungwe lanu

Kuchokera kwa anthu a m'mudzi

Kuchokera kwa azaumoyo ndi anamwino akumudzi

Mavuto okumana nao

Kodi mumakumana ndi mavuto otani posamalira odwala kumudzi?

Nanga mumatani pofuna kuthetsa mavuto amenewa?

Mungakhale ndi maganizo alionse a momwe ntchito ya chisamaliro cha odwala kumudzi ingapitire patsogolo mdera lanu?

-Zikomo chifukwa chololа kutengapo mbali-

Appendix 7: Letter to CHBC organization.

To:.....

.....

.....

Dear Sir / Madam

Re: REQUEST TO CONDUCT A STUDY AT YOUR INSTITUTION.

I am Rosemary Bilesi a Registered nurse/midwife at Mzuzu Central Hospital, but currently pursuing Masters in Community Health Nursing at Kamuzu College of Nursing. The aim of the study is to explore the experiences of CHBC volunteers. This is for improvement of Community home based care programs.

I am writing to request for your permission if I can conduct a study on "**Exploration of experiences of CHBC volunteers in HIV and AIDS care in Dowa district".** The study is in partial fulfillment of my Masters in Community Health Nursing.

The study requires me to interview volunteers who are taking care of HIV and AIDS patients in the community. I am expected to collect data from the month of July and August, 2014. Research ethics will be strictly adhered to for the safety and confidentiality of the participants.

Your assistance will be greatly valued.

Yours sincerely

Rosemary Bilesi (Mrs)

Appendix 8: Authorization Letter from KCN

University of Malawi
KAMUZU COLLEGE OF NURSING

PRINCIPAL
DR. A. MALATA, DipNur, MRM
B.Sc.MN, Ph.D.

P/BAG 1, LILONGWE, MALAWI
TELEPHONE: 265 (0) 1751 622/200
TELEGRAMS: NURSING
FAX: (0) 756 424
EMAIL: Principal@kcn.unima.mw
Website: www.kcn.unima.mw

Our Ref.: KCN/DPGS

3rd July 2014

The Chairperson,
COMREC
Private Bag 360,
Chichiri
BLANTYRE 3.

Dear Sir

RE: SUPPORT LETTER FOR MRS ROSEMARY BILESI

Mrs Rosemary Bilesi is a student at KCN pursuing a Masters Degree in Community Health Nursing. As a requirement for the fulfilment of a masters degree, she is required to submit a thesis. I am therefore writing to support the submission of her proposal tittled:
"***Experiences of CHBC volunteers in HIV and AIDS care in Dowa District***".

Rosemary Bilesi has worked with her supervisor and the proposal is now ready for submission.

Thanking you in advance for considering her proposal.

Yours faithfully,

Abigail Kazembe, PhD.
DEAN FOR POSTGRADUATE STUDIES AND RESEARCH

Appendix 9 : Authorization letter from Dowa DHO

Telephone: + 265 282 200
Facsimile: + 265 282 200
Email :dowa-hmis@malawi.net

All Communications should be addressed to:
The District Health Officer

In reply please quote No. .....
Ministry of Health,
DOWA DISTRICT HOSPITAL
P.O. Box 25,
DOWA

REF. NO. DA/DHO/ADMIN/10

26th May 2014

Mrs Rosemary Bilesi
University of Malawi
Kamuzu College of Nursing
Private Bag 1
Lilongwe

REQUEST TO CONDUCT A STUDY IN DOWA DISTRICT

Refer to the above subject matter in which you requested this Hospital to conduct a study on "***Experiences of CHBC volunteers in HIV and Aids care***".

I write to inform you that the Management has no object for you to conduct the Research but we would request you to bring the Study Proposal so that the Management should study it before you conduct the research.

Margret Kalanda (Mrs)/ DPHSA
FOR: DISTRICT HEALTH OFFCER

Appendix 10: Authorization letter from Light House (Pilot study)

LIGHTHOUSE

Tel: (265) 1 758 940 ext 112/0111735880
Fax: (265) 1 758 941
Cell: (265) 8 88 892 523
Email: samphiri@lighthouse.org.mw

Kamuzu Central Hospital (Area 33)
P.O. Box 106
Lilongwe
Malawi

Our Ref: LH/SP/bm/0303205

6th June 2014

Mrs Rosemary Bilesi
University of Malawi
Kamuzu College of Nursing
Private Bag 1
LILONGWE

Dear Mrs Bilesi

RE: REQUEST TO CONDUCT A PILOT STUDY

Thank you for your letter dated 12th May 2014 on the above subject.

Lighthouse is pleased to accommodate you to conduct a pilot study and be advised that you can proceed with pre-testing your data collection tools and be reminded further to send in copies of final research findings for our records.

Yours faithfully

Prof Sara Phiri
EXECUTIVE DIRECTOR

Appendix 11: Clearance certificate from COMREC

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.08/14/1609 – Exploration of experiences of community home based care volunteers in HIV and AIDS care in Dowa District by Rosemary Bilesi

On 3 November 2014

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. C. Dzamalala- Vice—Chairperson (COMREC)

Approved by College of Medicine

03 NOV 2014

(COMREC) Research and Ethics Committee

05/11/2014

Date