

**HOME BASED CARE (HBC) VOLUNTEERS' KNOWLEDGE ATTITUDE  
AND PERCEPTION OF IDENTIFICATION TREATMENT AND REFERRALS  
OF COMMON SYMPTOMS OF ACQUIRED IMMUNE DEFICIENCY  
SYNDROME (AIDS) IN BOTSWANA**

**PATRICK AKHIWU**

**STUDENT NUMBER: AKHPAT001**

**THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF  
MASTERS OF PHILOSOPHY (MPHIL) - PALLIATIVE MEDICINE  
SUPERVISOR: DR LIZ GWYTHER**

**FACULTY OF HEALTH SCIENCES**

**UNIVERSITY OF CAPE TOWN**

**2016**

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## **ACKNOWLEDGEMENTS**

I would first wish to thank my supervisor, Dr Liz Gwyther, CEO of Hospice Palliative Care Association, and Palliative Medicine Programme Convenor, Faculty of Health Sciences, University of Cape Town, South Africa. I do not have enough words to express my gratitude for her patience, guidance, understanding, belief and support during the difficult phase of my life that coincided with this study. I also wish to thank other members of my team, and staff of the department, especially Mrs Naomi Fray for her continuous gentle encouragement.

The support and sacrifice of my family has been invaluable during this time. For the many times I was not there – Oseje, Aizenose, Yetu, Ebosetale, and my dearest wife Elizabeth, you are my jewels of inestimable value.

This page would be incomplete without giving praises and glory to my Lord Jesus Christ for his never tiring work and blessings in my life.

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## **LIST OF ACRONYMS**

<b>AIDS</b>	Acquired Immune-Deficiency Syndrome
<b>APCA</b>	African Palliative Care Association
<b>ARV</b>	Anti-Retroviral
<b>CHBC</b>	Community Home-Based Care
<b>HIV</b>	Human Immune-deficiency Virus
<b>HPCA</b>	Hospice and Palliative Care Association of South Africa
<b>MTP</b>	Medium-Term Plan
<b>NACA</b>	National AIDS Coordinating Agency
<b>NACP</b>	National AIDS Control Programme
<b>NGO</b>	Non-Governmental Organisation
<b>PLHIV</b>	People Living With HIV/AIDS
<b>PMTCT</b>	Prevention of Mother-to-Child Transmission
<b>STD</b>	Sexually Transmitted Diseases
<b>UNAIDS</b>	United Nations Programme on HIV/AIDS
<b>UNDP</b>	United Nations Development Programme
<b>WHO</b>	World Health Organisation

## ABSTRACT

Home based care is a major intervention in the management of HIV/AIDS and other illnesses in need of palliative care, especially in situations where resources are limited. The challenges associated with HIV/AIDS infection in Botswana resulted in the training of home based care volunteers (HBCV) to assist in the fight against HIV/AIDS. The HBCV regularly visit and assist ill patients at home. They provided support with home activities and basic health care. They are to note changes in their clients' condition, and, if necessary, report to the home based team at the clinics for further action. The purpose of this study was to explore their knowledge, attitude, and perception in the identification, management, and referral of common symptoms of HIV/AIDS.

### METHODOLOGY

A cross sectional study of thirty three HBCV participants using a semi-structured interview guide was carried out. Closed and open ended questions were used to collect sociodemographic data and explore their knowledge, attitudes, and perception in relation to the identification, management, and referral of common symptoms of HIV/AIDS. A 5 point Likert scale was used to assess their confidence with caring for different symptoms. The response to the open-minded ended question were coded and analysed qualitatively using thematic analysis.

### RESULTS AND CONCLUSION

Most of the participants were women. The study revealed that fatigue, weakness and pain were the symptoms most identified by HBCV. Other symptoms like diarrhoea were also identified with HBCV demonstrating satisfactory basic knowledge and management of these symptoms. They were aware of common symptoms of opportunistic diseases like tuberculosis and the need to refer such patients. Majority of HBCV were "comfortable" or "very comfortable" with their role of referring patients for symptom management.

This study exposed the negative experiences of HBCV, which included stress, fatigue, helplessness, dealing with difficult families, fear of HIV infection, and death of clients. It

also highlighted their positive experiences of community appreciation, financial reward, providing symptom relief, spiritual development, increased knowledge, and having a sense of "Botho" (humanness and community responsibility).

This study showed the knowledge of the HBCV in relation to HIV/AIDS and associated symptoms. It also presented their attitude and perceptions with the management and referral of these symptoms.

# **CHAPTER 1.**

## **INTRODUCTION/BACKGROUND**

*“We are threatened with extinction; people are dying in chillingly high numbers. It is a crisis of the first magnitude”*- President Festus Mogae of Botswana (Mogae FG 2000).

### **THE AIDS EPIDEMIC**

Botswana in Southern Africa has an HIV/AIDS prevalence of 23.4%, the second-highest in the world after Swaziland (UNAID 2014). A population of about 2.1 million with about 300,000 living with HIV further underlines the importance and impact of HIV/AIDS in the life and economy of Botswana (UNAID 2014).

HIV/AIDS is also a global problem responsible for over 60 million infection worldwide, and a related cause of 30 million deaths (UNAIDS 2010). In 2013, there was 1.5 million AIDS-related death, 2.1 million new infections and 35 million people living with HIV (UNAID 2014).

The UNAID 2014 report shows that Sub-Saharan Africa is the region in the world that is most affected by HIV/AIDS. By the end of 2013, there were 24.7 million HIV-infected persons in Sub-Saharan Africa, which is 71% of HIV infection worldwide including 1.5 million of adult new infection and 210,000 of new HIV infection among children.

HIV/AIDS was reported to be the primary cause of death in this region, with 1.1 million AIDS-related death. The impact of HIV/AIDS on this region is further emphasized by the report that over 14 million children in Sub-Saharan Africa were estimated to have lost one or both parents to HIV/AIDS.

The southern Africa countries, which include Botswana, is responsible for most of the HIV/AIDS cases, in Sub-Saharan Africa.

### **IMPACT OF HIV/AIDS ON BOTSWANA**

Located in the middle of Southern Africa, Botswana is a land locked country with an area of 582,000 square kilometers (Botswana Housing and Population Census, 2001). It

is bordered by Namibia, South Africa, Zambia and Zimbabwe, with Setswana as the national language while English is the official language of government. In Botswana, the number of HIV/AIDS cases had increased at a high rate from 1985 when the first AIDS case was reported. It was then attributed to homosexuality and foreigners and regarded as alien to Botswana (MacDonald, 1996). However, the report from the AIDS/STD Unit of the Ministry of Health in the Medium Term Plan 2 (1997-2002) revealed the devastating impact of HIV/AIDS on Botswana and its health care system. The report stated that, in the paediatrics and medical wards of the two main referral hospitals, 50% of the beds were occupied by patients with HIV/AIDS-related illness (AIDS/STD Unit, 1997). The impact among children was so devastating that it was estimated that about 90% of deaths in the under-five age group in Botswana will directly or indirectly be linked to HIV/AIDS by 2015 (Epstein BG, 2004). Apart from the high infection related deaths children were also affected with about 95 000 children losing at least one parent, and some children looking after younger siblings or sick relatives. The psycho-socio-cultural consequences are that there will be an increase in the number of street children, a high burden on surviving parents, grandparents, extended family, and general disruption of the family structure.

The high prevalence of HIV resulted in more people needing chronic medical care and attention in the medical facilities of Botswana. This need stretched the human and material resources, diverting more bed spaces to HIV/AIDS care in hospitals and thus reducing available in-patient hospital care for other acute conditions. The wards in hospitals were congested and overflowing with most of the patients too ill with HIV/AIDS for discharge home. There were insufficient numbers of staff to provide services and the available ones were overworked and facing or experiencing burnout. All these resulted in an enormous strain on health facilities and their quality of care. Even in 2001, the AIDS/STD Unit of the Ministry of Health baseline study showed that the increasing number of AIDS patients along with the cost of running health care in Botswana makes it difficult to maintain the country's health system (NACP 31, 2001).

The socio-economic effect of HIV/AIDS has been devastating. There has been significant income loss in households. One in five families reportedly lost substantial income as a result of providing HIV/AIDS care. Families experienced food shortage,

lack of basic needs, economic insecurity, and home breakups (Rajaraman, Russell, & Heyman, 2006). These outcomes were not unexpected. It had been estimated that the Gross Domestic Product (GDP) would be 2.6% less annually than it would have been if HIV/AIDS was absent in those countries with a 20% minimum HIV prevalence (Bonnell, 2000). Botswana falls into this group. However, by 2001, the macroeconomic impact was expected to be greater with a fall in the estimated annual GDP growth from 5.5% before HIV/AIDS to a range of 1.5 to 2.5 in the next decade due to the pandemic. (Botswana Institute for Development Policy Analysis, 2000), (MacFarlane, M., & Sgherri, 2001). Apart from the fall in GDP, Botswana was expected to incur additional cost from the introduction of free antiretroviral treatment, higher health care spending, increased public sector and social support cost. This was estimated to rise above 5% of the GDP.

#### BOTSWANA'S RESPONSE TO THE HIV/AIDS EPIDEMIC

It was obvious that all areas of society, including the family, community and economy were seriously affected by HIV/AIDS, and urgent actions needed to be taken to reduce this impact. The government of Botswana then under President Festus Mogae initiated strategies to combat the situation. HIV/AIDS was handled as a national disaster. Appeals were made to non-governmental bodies and the international community for assistance (Mogae, 2000). The government of Botswana took a leading role in Africa by getting directly involved and providing resources internally, creating partnership externally, in the effort to address HIV/AIDS and its impact. Initiatives, measures and definite programmes were put in place by the government alone or with assistance from the non-governmental organizations and assisting nations. The government response may be divided into three stages. The first stage was in the period, 1987 to 1989. This was the period of early response, with a focus on the elimination of HIV transmission, starting with a focus on eliminating transmission through blood transfusion. The second stage was from 1989 to 1997 and referred to as the first Medium Term Plan (MTP). Programmes to tackle education, information and communication issues were put in place with emphasis on changes in sexual behaviour with the aim of reducing sexual transmission, and other high risk activities. This was also the time that the Botswana

National Policy on AIDS was adopted (Ministry of Health, 1995). The next stage was from 1997 onwards. Strategies involving education, prevention and comprehensive care were added or expanded. This saw the emphasis on public education especially youth education, free condom distribution, and prevention of mother to child transmission (PMTCT) of HIV/AIDS. Significant resources were put into voluntary counselling and testing. Highly active antiretroviral therapy (HAART) was introduced for citizens of Botswana who had tested positive for HIV. Botswana was the first country in Africa to implement ART accessibility on a wide scale. This was initially for all citizens who tested positive with a CD4 count of less than 200/L (UNAIDS 2006). The HAART eligible CD4 count level was later changed to a CD4 count of less than 250/L. This change was to reflect the international consensus that HAART should ideally be initiated before the CD4 cell count falls below 200cells/L (Botswana National HIV/AIDS Treatment Guideline, 2008).

A body responsible for mobilizing and co-coordinating a multi-sectoral response to HIV/AIDS, National AIDS Coordinating Agency (NACA), was formed in 1999. It was placed under the National AIDS Council, chaired by the President of Botswana, reports to the presidency, and had representatives from the public, private and civil societies. Health services in Botswana like most other countries are provided by the public and private sectors. However, they all operate under Botswana's health rules and regulations. The impact of HIV/AIDS was felt by all health sectors. They were all faced with the challenges of coping with the increasing demands on their resources by the effect of HIV/AIDS. With the high demand for these services, visible difficulties with coping, and the increase in the number of terminally ill patients, palliative care through the medium of formal home based care was initiated in Botswana (NACP 31, 2001).

## HOME BASED CARE

Home Based Care (HBC) is regarded as the care and provision of needed health services to an ill person and his or her family at home. HBC exists in different models, with the simplest model dividing HBC into two services. These are:

- i. Community related programs
- ii. Clinic based out reach programs (WHO , 1991)

Most programs integrates the two. In some cases, the care with the involvement of the family, training them in nursing care and enhancing psychosocial support for the caregiver and the patients (Jackson, 1992). Community Home Based Care (CHBC) refers to care given to ill persons in their homes. This care is holistic to include preventive, curative care as well as and palliative care. Palliative care on its own encompasses bio-psychosocial, cultural and spiritual care. These can be spread out into essential elements that determine the effectiveness of the programme. These elements are education, staffing, care provision, continuity of care, supplies provision, financing, monitoring and evaluation of the programme (Hirschfield 2000).

### HBC Goals

Jackson and Kerkhoven (1995) describes HBC services as a mean of providing holistic support to patient and their families in their homes, thus reducing the need to source services in the hospital. This form of care was most needed in southern Africa. A report from the World Health Organisation showed that there was an increase in bed occupancy with 70 to 80% of beds occupied by PLHIV (WHO, 2002). The consequence of this is enormous pressure on health facilities that were already burdened with the challenge of health delivery in resource limited settings (Mc Donnell at 1994). By reducing the need for hospital admission, HBC goals are to decentralize AIDS management and to reduce overburdening in hospitals providing nursing care to patients at home.

### HBC Benefit to Patient and Family

HBC has multiple benefits for the patient being nursed at home (Jackson and Kerkhoven 1995). It saves on transport costs to hospital and time visiting hospital. In addition the patient is with family and less likely to feel isolated. They feel more supported, comforted and are thus able to cope better as they face serious illness and possibly death. However, this terminal situation has changed with the availability and accessibility of HAART, for patients adhering to treatment. For these patients HIV infection has changed to a chronic illness, with HBC supporting wellness and treatment adherence. For the relatives, they are able to spend more time with their loved ones and

provide support while at the same time they are able to attend to other important home issues.

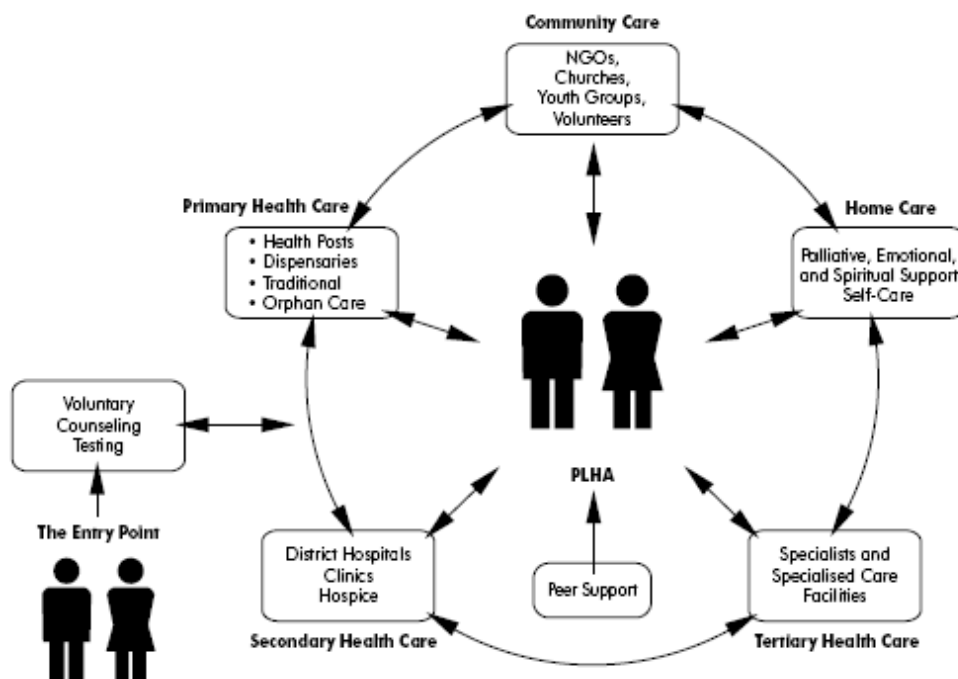
### HBC AND PALLIATIVE CARE

The importance of HBC services in addressing HIV/AIDS care and its benefits to PLHIV and their families cannot be over emphasized. In a review of home based care models by the African Palliative Care Association (APCA), major reasons underlining HBC care and support for HIV/AIDS are identified. These are facts that health care facilities are overburdened by needs for care related to HIV and that the practice of HBC fits in the cultural values in many settings where there is care for the sick and dying at home within the communities. This community Home Based care has been defined as care provided to the ill in their homes or more generally in their natural environments by families and available community resources (Hardings and Higginson 2003). The World Health Organisation defines Palliative care

(<http://www.who.int/cancer/palliative/definition/en/>) as “an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psycho social and spiritual problems”. According to WHO, palliative care may be provided through HBC in areas with limited resources. This relationship of palliative care with home based care is strengthened by the fact that palliative care involves physical, spiritual, palliative, social and material needs (APCA, ). However it must be mentioned that many HBC programs in Sub-Saharan Africa do not provide a comprehensive palliative service but selectively choose aspects of palliative care they would integrate into their HBC services. The problem of inadequate pain relief due to lack of trained professional staff and/or pain medication is a major contributor to the inadequacy of HBC services in providing comprehensive palliative care. This is an area that needs to be vigorously explained to enhance full integration of palliative care into HBC (APCA). A good example of the provision of palliative care in a HBC setting is seen with the South African Hospice Palliative Care Association’s Integrated Community-based Home Care (ICHC) model (Els & Power, 2006). This model demonstrates a patient centred

approach with the patient living with HIV and family as the core of the programme. They are supported by extended families, neighbours, and other agencies which form the micro-community that also care for the patient and family.

Herewith below is a figure showing the relationship of palliative care in HBC in a community (Gwyther et al, 2006).



Source: Gwyther L, Merriman A, Mpanga Sebuyira L, Schietinger H, editors. A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa. 2006. Kampala, Uganda: APCA; 2006.

For Palliative care to be well integrated into HBC for PLHIV , the HBC program will need to involve strategies that include training and education, access to essential medicines including morphine for pain management and appropriate referrals.

### HOME BASED CARE (HBC), PALLIATIVE CARE AND THE HBCV IN BOTSWANA

The Gaborone Declaration on community home based care at the first regional (SADC) community home-based care conference in 2001 defined community home based care. as the care given to an individual in his/her own environment, by his/her family and supported by skilled welfare officers and the community, to meet not only the physical

and health needs, but also the spiritual, material and psycho-social needs (Gaborone Declaration on CHBC, 2001).

Suffering may be due to different factors that include physical, emotional, spiritual and psychosocial issues. The relief of these includes a multifactorial approach and team work involving practitioners in these areas. Members of a comprehensive palliative care team may therefore include the doctor, pharmacist, social worker, psychologist, clergy, nurse, dietician, physiotherapist, and other professionals that may play roles in reducing the suffering of the patient in need of palliative care. The components of Palliative care services include symptom control, effective communication, rehabilitation, continuity of care, terminal care, support in bereavement, education, and research (O'Neill B, Fallon M. 1997). Palliative care addresses care of patients and their families. In Botswana, home based care is focused on HIV/AIDS care. Though home based care is one of the models for delivering palliative care services to PLHIV, palliative care is not restricted to HIV/AIDS. Palliative care and by extension home based care's essential role in the prevention and relief of suffering goes beyond HIV/AIDS to include the non-communicable diseases.

Home based care was launched in Botswana in 1999 with the purpose of decongesting the hospitals to free beds for acute care and other conditions, treat patients at home and refer from home when necessary to reduce unnecessary hospital admissions. A proper functional referral system is part of the aim of palliative care towards maintaining continuity of care. In this way, patients discharged from hospitals are monitored to ensure they receive proper care and return to the health facilities when necessary. Palliative care in the form of home based care services was introduced to facilitate the use of counseling and supportive services. Counseling services are provided to the HIV/AIDS patient and their families, and they may be referred to the social welfare unit and other supportive bodies as and when necessary.

The palliative care HBC programme is coordinated from the AIDS/STD units of the Ministry of Health. There is a national coordinator who is responsible for all districts in

Botswana, while the district coordinator runs the programmes at district levels and reports to the national coordinator. At the district level, personnel involved in home based care include social workers, nurses, and trained home based care volunteers (HBCV).

The home based care volunteers receive training focused on home based care. After the training, they are expected to assist patients in many ways that include bathing, feeding, massaging, counselling, ensuring proper use of medical treatment, ensuring proper attendance of medical checkups, training family members and performing other activities to improve their patient's wellbeing. They also help to clean the house, get involved in activities such as gardening and poultry farming for the benefit of their client and possibly generate income for their clients. They assist the very ill HIV/AIDS patients in different ways including ensuring the sometimes weak or bedridden patients stay in a clean home environment hence cleaning the home. There is a cultural aspect – the spirit of Botho that urges them to help in any way they can. They also play a crucial role in the referral system. They are expected to be alert for changes in their client's condition and report appropriately to the home based team at the clinics for further action. The services of the home-based caregiver have tremendously helped in out-of-hospital care of AIDS patients and prevented many consequences associated with overburdening the health system. As mentioned above, they are usually the first person to be confronted with complaints and symptoms of the patient. They assist in educating the family and nursing the patient at home. They take decisions regarding the health of the patient, referring when necessary to the local clinic for further management of the patient. They are part of the primary care team of the health care system. This highlights the importance of the required knowledge, attitude and perception regarding these roles above. It is of great concern, if the HBC volunteers do not have the required knowledge, attitude and perception. This would ultimately result in erroneous identification of symptoms and inappropriate interventions, in addition to poor quality referrals. This may result in a worsening of the situation that the HBC programme was supposed to assist. There may be overburdening of the hospital and health system.

All of these underlines the importance of knowing how much the HBC volunteer knows, and look at his/her treatment and referrals of common illness/symptoms associated with AIDS. It is necessary to examine challenges they face in their work. This is important to the patient, HBC volunteer, community and the government. This information would help to better organize and improve the HBC service, plan trainings and help to address the needs of the HBC volunteers.

## **CHAPTER 2.**

### **LITERATURE REVIEW**

#### **INTRODUCTION – Symptoms of HIV/AIDS**

This review is to gain an understanding and background of available information with regards to HIV/AIDS related symptoms and Home Based Care management of these symptoms.

In this review, HIV, AIDS, Home Based Care, AIDS symptoms, AIDS knowledge, were some of the keywords in the literature search. They were explored in more details. Literature from different reliable sources was searched. These included published books, peer-reviewed journals, and reputable electronic search engines. These search engines include EBSCOhost, Proquest, United States National Library of Medicine (PubMed) and the Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus). Search engines and web directories were used to search and compile a list of keywords and phrases. Inclusion of relevant terms, exclusion of irrelevant terms, and phrase searching were applied for a more specific search.

Though there have been some research on the presentation of symptoms of HIV/AIDS by PLHIV, there has been little research with regards to symptoms identified by trained HBC volunteers and their management of these symptoms, especially in sub-saharan Africa. There are some symptoms usually associated with PLHIV when they become ill. These symptoms experienced by PLHIV may confront the HBCV regularly as they visit their ill clients at home.

HBCV are expected to have adequate knowledge of HIV/AIDS and symptoms of related illnesses usually seen with PLHIV. HBCV care for these patients, so they are also expected to contribute to the management of these symptoms and illnesses.

Symptoms are defined as the perception of an abnormal physical, emotional or cognitive state by a patient (Wilson and Clearly 1995). Another view of symptoms describes them as perceived indicators of change in normal functioning in relation to the patient experiences (Hergyvary, 1993). However, a more comprehensive explanation of symptoms was the definition by the University of California, San Francisco School of

Nursing Symptoms Management Faculty group (University of California 1994). They defined symptoms as the subjective experiences reflecting changes in the person's biopsychosocial sensation or cognition. This explanation from the University of California involves three dimensions that were interrelated. These were -

- symptoms experience
- symptom management strategies provided by patient family, health care providers and the health care system and
- symptoms outcome

This study investigated common symptoms observed by the HBCV and the interventions they employ to address these symptoms experienced by the PLHIV. Researchers from different parts of the world highlighted various symptoms noticed in PLHIV.

Tsai, Hsuaing and Holzener in a study in Taiwan of patient with HIV/AIDS, found out that nausea, pain, anxiety, vomiting, diarrhea, fear and lack of appetite were the symptoms described by HIV – infected participants (Tsai Y, Hsuaing P and Holzener,2001). The health care providers however frequently observed nausea, anxiety, diarrhoea, fever, fear, pain and vomiting among the PLHIV. The study further mentioned that PLHIV experience many symptoms related to opportunistic infections and malignancies and side effects from prophylactic and therapeutics interventions. From Italy Fantoni et al (1997) showed that the most frequent symptoms of PLHIV were fatigue(65%) anorexia (34%) cough (32%) pain (21%) and fever (29%). Rosenfeld and others in the USA found out that the most prevalent of the symptoms were worrying (86%), fatigue (85%), sadness (82%) and pain (76%).

Reilly and others revealed that there was an average of 16 symptoms among PLHIV with over half of them complaining of shortness of breath, cough, dry mouth, and lack of appetite, fatigue, weakness, weight loss, and headache Similarly in Taiwan, Hsuaing and others found out that PLHIV present with multiple physical symptoms that included weakness, fatigue, and shortness of breath with activity, dry mouth, and thirst. The psychological symptoms were mainly insomnia and depression. (Hsuing et al, 2000). The prevalence of mental illness among HIV-infected patients was further supported by

Atkinson et al and Chuang et al who found out that such mental illness was prevalent among PLHIV especially depression, anxiety and substance abuse (Atkinson et al, 1988) (Chuang et al, 1989).

Some related studies in Sub-Saharan Africa on symptoms of HIV/AIDS were mostly carried out in communities with challenges in readily available and accessible active retroviral therapy (ART). Makoae et al (2003) looked at PLHIV in four southern African countries of Botswana, Lesotho, South Africa and Swaziland. They found that where ART was not readily available, there was a strong relationship between intensity of symptoms and their frequency. They highlighted the impact of the socioeconomic status of patients with symptoms frequency of patients, with fewer symptoms associated with patients having enough money for their daily expenses.

Symptoms distress is one important aspect of quality of life which is a multi-dimensional construct. The presence of different symptoms in a PLHIV is thus a strong indicator of impaired quality of life (Wachtel et al., 1992). Physical symptom distress is regarded as an independent predictor of impairment in the assessment of primary activities of daily living. Cleary and others (1993) stated that the net impact of these symptoms distress is more important than the presence of specific symptoms in contrast to Rosenfeld et al. (1999).

On the other hand, Revicki, Wu and Murray (1995), in their study showed the extensive impact of symptoms beyond the physical manifestations on the human body. In reviewing Revicki, Wu, and Murray, they highlight the fact that the effect of symptoms goes beyond the physical to affect the psychosocial being. They emphasized the association of increased physical symptoms with pain, physical role functioning, mental health, depression, cognitive function, social function and changes in health perception. In contrast to the broader biopsychosocial view of symptoms in relation to PLHIV, initial and earlier studies on symptoms in PLHIV focused on symptoms in relation to the particular physical system or parts of the human body involved. These studies in the very early years of the HIV/AIDS manifestations, though well conducted, did not look at these symptoms holistically. Monteagulo et al (1991) and Calabrese et al (1991), studied rheumatic symptoms in PLHIV. The study by Collier et al (1992) focused on

central nervous system symptoms while Urich et al (1992) reported on the gastrointestinal symptoms.

Later studies have become broader and involved the whole body. They were not just focused on symptoms of particular systems but at general symptoms (Fantoni et al 1997; Yun Fang Tsai et al 2002; Peltzer & Phaswana–Mafuya 2008). This change in focus enhanced a more comprehensive and holistic outlook on symptoms and their impact.

Studies on symptom distress in PLHIV have emphasized the importance of assessing and treating these symptoms to improve the quality of life of PLHIV (Rosenfeld et al, 1999). The studies highlight the relationship between symptom distress and quality of life and importance of effective symptom management. However, these research studies were carried out by conventional medical teams, focusing on nurses and doctors and not on other members like HBCV, who are usually the first to encounter these symptoms in a home based care context. As the first members of the team confronting these cases in resource-limited settings, they may have to initiate symptom management while awaiting the interventions of other members of the HBC group. Though it may be argued that these HBCVs are not trained enough to manage symptoms, these studies revealed shortcomings in symptom management by the better-trained health personnel in the HBC teams. The researchers have noted that though the usual medical team members of nurses and doctors attending to PLHIV have significant role in detecting and managing these symptoms, they have not done that well (Gebbie 1995; Zeller Swanson and Cohen 1993). Nurses tend to underestimate the frequency and severity of symptoms (Holzemer et al 1999; Reilley et al 1997) while doctors and physicians poorly recognize PLHIV symptoms (Fontaine, Larue and Lassauniere, 1999). They were reported to underestimate and undertreat symptom distress (Rosenfeld et al, 1999). Studies showed that symptomatic treatment for pain, diarrhoea, nausea and vomiting was under-prescribed (Larue et al, 1994). However, the prevalence of symptoms was also underestimated.

In the study by Tsai et al (2002) in Taiwan, the management of diarrhoea among PLHIV did not include the use of ORT, among the many ways of managing diarrhoea. They mentioned the eating of vegetables and fruits, taking anti-diarrhoeal drugs,

drinking more water and enduring the diarrhoea. The study respondents also they would send the patients to Emergency Rooms or OPD as additional measures for the diarrhoea.

Pain as a primary symptom in PLHIV was not emphasized in many studies despite its multiple effects on the wellbeing of a PLHIV, and when studied has been found to be unsatisfactorily managed, underlying the emphasis that should be placed on this symptom in researches with PLHIV. An analysis of management of pain in PLHIV showed that about 85% of them were receiving inadequate analgesics (Breitbart 1996).

## PAIN IN PLHIV

Pain has been found to be one of the most commonly reported symptoms among PLHIV and studies have confirmed that it is common at all stages of the disease among PLHIV (Parker, Stein & Jelsma, 2014).

Parker et al conducted a systematic review of the literature to establish the prevalence and characteristics of pain and explore pain management in PLHIV. This review was of the literature between 1982 to 2012. It revealed that the prevalence rate for pain in PLHIV has not diminished in the 30 years of these studies. It also showed that pain associated with HIV and AIDS presents at multiple sites with a range of severity that suggests that many different pathological processes contribute to pain at one time. This involvement of various contributors to pain suggests that the biopsychosocial approach is the best way to assess and manage pain in PLHIV.

As stated earlier pain among PLHIV is very common (Cox and Rice, 2008). However, the pain experienced by PLHIV and their possible cause varies. It is postulated that the pain experienced by PLHIV may be due to different factors that include the direct result of the virus in the peripheral or central nervous system (Parker, Stein & Jelsma 2014). Other causes include the immune suppression with the complications of opportunistic infection, and side effects of the antiretroviral treatment, Hewilt et al in assessment of pain syndrome in a quality of life study found that headache (46%), joint pain (31%), polyneuropathy pain (28%) and muscle pain (27%) were the most common pain diagnosis among PLHIV. They also found that 45% of the pain syndrome was somatic, 15% visceral, 19% neuropathic, and 4% are idiopathic in nature.

However, despite these studies, it has been difficult to evaluate the relative impact of pain in PLHIV due to the wide range of prevalence of pain among studies with PLHIV. Some studies showed lower prevalence of pain among asymptomatic PLHIV. Tran et al (2011) presented a pain prevalence of 10.9% among PLHIV. This lower prevalence was among ambulatory asymptomatic patients who most likely had not deteriorated enough to require home based care. While Myezwa et al (2011) also reported very low prevalence of pain, Norval (2004) in a study carried out in South Africa found prevalence of over 90% of pain among PLHIV. Norval's study confirms the review conducted by Beitbart and Passik (1996 for the International Association for the Study of Pain (IASP) in which they emphasized the prevalence of pain and its undertreatment among PLHIV.

This study which aims to explore pain and other symptoms as they present to PLHIV in the Botswana context, will contribute to the current literature on care of PLHIV.

## EDUCATION AND KNOWLEDGE

The home-based caregiver in Botswana has not necessarily received a formal medical or nursing training. In fact in searching the computerized literature few studies on educational needs of caregivers were found.

A literature review by Thielmann P in the American Journal of Hospice and Palliative Care (July-August 2000) found very few studies on the educational needs of caregivers. They all showed similar conclusions, a need for information on meeting the physical needs of the patients, community resources and the patient's illness (Thieleman, 2000). There is a necessity for more work to address those needs and empower the caregiver of terminally ill AIDS patients.

The home-based care program in Botswana involves family members in the care of terminally ill AIDS patients but ignorance still plays a role in discrimination regarding caring for terminally ill AIDS patients especially among the young in Botswana. Some believe a person could get HIV infection by sharing meals with an HIV-infected person. About 11% of respondents in a study conducted in Botswana by Letamo G (J Health Popul Nutr.2003) reported unwillingness to care for family members with AIDS.

Their reason, as mentioned above, was related to their ignorance and fear of inadequacy in providing care to terminally ill AIDS patients. The study showed that in Botswana, home based care was provided mainly by women. Another study (Lindsey et al , J Health Popul Nutr.2003) in Botswana reported that women feel overwhelmed with the magnitude multiplicity of tasks and lack of basic care giving education associated with home based care.

Bellani et al (1996) described the fact that burnout was more evident among carers of HIV/AIDS patients than in other fields. Ditsheko (2006), also in her study in Botswana,found that all participating caregivers for PLHIV experienced some burnout due to the unique stressors they were exposed to and multiple factors. She suggested the use of continous counselling for the caregivers to enable them adapt more effective strategies).. They attributed this burnout to multiple factors that included social stigma, fear of infection, and inadequate knowledge and support.

The characteristics and needs of home based care workers in Botswana is not really different from that of most other developing countries where women play the major role. The community worker in the home based care project visits homes to help in providing care, counselling, educating/instructing family caregivers, and referring patients for further medical treatment (Henry, 1995). This is what caregivers of the home-based care program in Botswana are involved in almost daily.

How much knowledge of AIDS and the associated symptoms do they have to help them in carrying out these roles? This knowledge needs to be assessed. In Botswana, a deficit of knowledge among these home based caregivers had been observed in a previous study. This study by Ndaba-Mbuta and Seloilwe (2000) showed a high rate of readmission to hospital of patients with complications suggesting poor quality care at home and elderly caregivers being diagnosed HIV positive suggesting that transmission might have occurred during the process of care giving. Findings indicated that some of the caregivers lacked knowledge and skills in the provision of care including professional and material support. .

In neighbouring South Africa despite relatively higher resources, the need for assessing and empowering the community caregiver also exist. A study by Uys LR( J Clin Nurs. 2002) on home based care in South Africa showed that the community home based

care giver usually finds it difficult to cope with the complexity of problems they face in their job of home based care.

Inadequacy in knowledge may also mean poor or inappropriate referrals by the home-based caregiver. With poor knowledge in the management of minor ailments, leading to higher number of referrals, the hospital resources may become overwhelmed (Zimba and McInerney, 2001).

Inadequate knowledge and skills as mentioned earlier leaves the home caregiver worried and poorly motivated to carry out their duties (Olenja, 1999). In some cases where the caregiver may have satisfactory knowledge there unfortunately maybe poor attitude and practices (Mbanya et al, 2001).

The need for assessing the knowledge and empowerment of home caregivers is not limited to sub Saharan countries or African countries alone. A Study in Brazil by Gir E and Reiss PK (Rev Esc Enferm USP 2001) emphasised the need for assessing and empowering the home-based care workers to assist them improve their services. Even in developed countries like the United Kingdom the need to empower the home based care giver was highlighted in a study carried out in South West London among caregivers by Duffy and Moore (Br J Community Nurse 2000). The study showed that the majority of respondents felt they did not have the information they needed about HIV and AIDS despite the fact that some of them had cared for at least a patient who was either HIV positive or had AIDS.

## RATIONALE FOR THE STUDY

Though there have been some research on presentation of symptoms of HIV/AIDS by PLHIV, there has been little research with regards to symptoms identified by trained HBC volunteers and their management of these symptoms, especially in Sub-Saharan Africa.

The symptoms experienced by PLHIV may confront the HBCV regularly as they visit their ill clients at home. The HBCV are expected to have enough knowledge to identify these symptoms, initiate early management and possibly refer if necessary.

For these needs of the home based care giver to be addressed we need to asses and evaluate their knowledge, attitude and perception of identifying, treating and referring common symptoms of AIDS.

## **AIM AND OBJECTIVES**

### Aim of the Study:

The aim of this study is to determine the knowledge of HBC volunteers, their attitude and perception in relation to the diagnosis, treatment and referral of common symptoms associated with acquired immune deficiency syndrome (AIDS) in Botswana.

### Objectives:

- To determine the demographic characteristics of HBC volunteers.
- To explore the perception by HBCV of common symptoms associated with AIDS in Botswana, their diagnosis, treatment, and presentations.
- To assess the HBC volunteers knowledge of HIV/AIDS symptoms and treatment.
- To look at issues related to the referrals by HBC volunteers of common AIDS associated illnesses.

## **CHAPTER 3.**

### **METHODOLOGY**

#### **3.1 STUDY DESIGN**

This is a cross-sectional study of knowledge; attitude and practice of Home Based Care (HBC) Volunteers) in Maun and surrounding areas. It includes qualitative and quantitative components.

**3.2 STUDY SITE** The study took place in the area of Maun, Botswana. HBC activities usually take place at the home of the patients.

#### **3.3 STUDY POPULATION AND SAMPLING**

The study population is all Home Based Care Volunteers (HBCV) who have been trained to provide home-based care services to residents in need of such services in Maun, Botswana.

This study was constructed to show an in-depth understanding of the knowledge, attitude and perception of HBCVs in their identification, management and referral of PLHIV. This would require a more qualitative study approach. A homogeneous sampling strategy was selected as appropriate as the participants have a similar background of being HBCV and similar experiences of caring for PLHIV. Based on this in-depth interviewing approach an average sample number of 30 was estimated as needed to achieve that (Patton, 2001).

##### **3.3.1 Inclusion Criteria**

Home Based Care Volunteers working with the Maun and surrounding clinics were eligible for inclusion. All HBCV working with the clinics by requirements must be over 18

years of age, have a minimum of junior secondary school education and must be able to read and write.

### 3.3.2 Exclusion Criteria

HBCV, who were still receiving training in home-based care from the clinic nurses, and participated for less than a month in full HBCV activities.

## 3.4 DATA COLLECTION

### 3.4.1 Data Collection Tools

A semi-structured interview guide was developed in English. The questions were derived from discussion with health personnel involved in home based care and the author's experience. It is made up of open-ended questions with a few close-ended questions, asked of all respondents. The first six questions were to collect socio-demographical data from the HBCV (Questionnaire - Appendix A).

Open-ended questions were chosen to enable the researcher explore issues related to knowledge, attitude and practices of the HBCVs. The questions were to assist in assessing the attitude and experience of respondents with regards to caring and referring their clients. Open-ended questions enhanced better subjective understanding and grasp of the participants' attitude and practices, which are the main objectives of this study. The questions were developed after review of literature, discussion with the nurses involved in the training of HBCVs, the research supervisor, the medical team that supervises and receive referrals from the HBCVs, some patients receiving care from HBCVs, palliative care physicians, medical doctor colleagues usually involved in HIV management and some HBCVs from a neighbouring village. These discussions assisted with deciding on the questions to be included. Important points were collated and the questions were developed to assess participants' knowledge of HIV/AIDS, usual complaints they encounter with patients, symptoms they find challenging and their experiences of caring and referring their patients.

This was followed by questions exploring their knowledge regarding acquiring HIV infection, experience of common symptoms associated with AIDS, caring for patients with pain, diarrhoea, identifying tuberculosis, and assisting tuberculosis patients. A 5 point Likert scale was used to assess their confidence in caring for symptoms associated with AIDS and referral. This was rated from 1 for “very uncomfortable” to 5 for “very comfortable”.

The questionnaire allowed us to obtain data within the designed scope. The questions were asked in an order and format understandable to all HBCVs, including translation to the local Setswana language, to allow for comparison between answers.

#### *3.4.1.1 Pilot Study*

A pilot study was carried out among HBCVs in a clinic in the neighbouring village where the interviewer works. This was done before the first formal interview to enable our team to assess the questionnaires and possible logistical problems that may arise during the research interview. Five HBCVs participated in the pilot study. Content and Face validity were used to judge the questionnaire. Face validity according to Anastasi “refers, not to what the test measures, but to what it appears superficially to measure”. It is a weak measurement of validity. Initially on face value, the questionnaire was seen to measure what it was meant to measure. Once, face validity was confirmed; the questionnaires were assessed for content validity. Content validity refers to how items on the test represent the entire range of possible items the test should cover. The questions were reviewed, and rated by health practitioners involved in regular and daily care of HIV/AIDS patients and home-based care activities. They evaluated each question looking at how much it represents the variable to be tested. They also looked at what is not measured by the questionnaire. The result showed that the questionnaires were appropriate and understandable. However, we had to make minor changes to some of the questions to allow for better understanding of the questions and response.

#### *3.4.1.2 Validity and Reliability*

Polit and Hungler refer to the validity as the “degree to which an instrument measures what it is supposed to be measuring”. As mentioned above, the questionnaire was developed after extensive consultation with palliative care practitioners, nurses involved in the training of HBCVs, the medical team that supervises and receive referrals from the HBCVs, some patients receiving care from HBCVs, medical doctor colleagues usually involved in HIV management and some HBCVs from a neighbouring village. After the pilot study and minor changes made, the questionnaire was thought to be clear, understandable, and adequately covered the required content.

Polit and Hungler refer to the reliability of an instrument as “the degree of consistency with which it measures the attribute it is supposed to be measuring”. This study was done through the same questionnaire administered to all the participants whom all have a minimum of junior secondary school education.

#### *3.4.2 Data Collection Process*

The process of data collection involved the recruitment and training of research assistant, followed by the recruitment and informed consent of the participants, and conducting of the interviews.

##### *3.4.2.1 Recruitment and Training of Research Assistant*

The research assistant was selected based on her Family Nurse Practitioner (FNP) background, her previous experience with research, and the fact that she had prior experience with supervising HBCVs. She also had a good understanding of the culture of the people of Maun. We went through a review of the research methods and ethics with emphasis on ethical guidelines related to interviewing, and identifying stress in the study participants. The interviewer was not part of the team that normally supervises the respondents. This was to encourage the participants to discuss and comment freely, fairly and independently without fear or expectation of reward. She was also very fluent in Setswana and English. The questionnaire was completed by the research assistant recording participants responses.

The Family Practice training of the nurse made it easier to go over the area of open-ended questions. Prior to the study, we went through the steps involved and the possible difficulties she may encounter.

#### *3.4.2.2 Recruitment and informed consent of the participants*

The HBCVs available in the clinics were approached. They were informed and educated about the study. They were specifically advised of their right to participate or not with no penalty or reward. Emphasis was placed on confidentiality, anonymity, and the choice of withdrawing at any time during the study. The nurse conducting the study as a research assistant had previously been involved in research and was aware of the importance of informed consent. She was further trained about this research proposal, and a review of research ethics training was provided.

Thirty-five HBCVs initially gave their consent, but two later declined to provide data and decided not to participate.

#### *3.4.2.3 Conducting the interview*

Those willing to participate were given the consent form to sign before the interview.

The research assistant conducted the interview and noted the responses. The answers were re-checked with the participants to ensure the accuracy before ending the process. Though participants were all able to express themselves in English (they regularly have to fill a booklet regarding their patients that are regularly checked by the clinic nurses) they were given the option of using the local Tswana language if they felt that would allow them to express themselves better.

The researcher and research assistant regularly checked the responses collected after every five for errors or misunderstandings. The responses from the HBCVs were recorded on the questionnaire to reflect the exact words as much as possible.

#### *3.4.3 Data storage and confidentiality*

All responses and information from the HBCV were recorded on the forms for interview, and on attached papers.

To ensure confidentiality and avoid identifiers, names of respondents were not recorded on any of the documentation, and all completed interview documents were securely locked up in a cupboard in the office of the researcher.

#### 3.4.4 Data Analysis

The quantitative demographic data and Likert scale data were statistically summarised into graphs, tables and pie charts from excel spreadsheets. The Likert scale assessed their feelings and attitudes about caring and referring patients to symptoms associated with AIDS.

HBCVs' responses to questions assessing their knowledge were also analysed and presented graphically for easy comparison of different responses.

The open-ended questions were analysed qualitatively. The researcher developed familiarity with the narrative answers by reading and re-reading the responses. It was a recursive rather than a linear process involving a constant and continuous review of the data set. The aim of the repeated study was to look actively for and identify patterns, starting with the identification of an idea, word or phrase. These ideas with their common features were then listed, and initial codes produced from this data.

After coding all the extracted data, they were then collated inside each code and sorted into potential themes. Brink and Woods describe themes as data grouped around a central issue. Using thematic analysis for the responses means we stay alert for potential new themes, and check if they fall under already existing categories or not. New categories may also be created. It means exploring the responses till 'full exploration' has been achieved..

The different codes were analysed and re-analysed to see how they combine into overarching theme. The relationship between the codes, themes and different levels of themes were identified, with some codes forming sub-themes, main themes or not fitting at all. These potential themes were refined to see if the data within them cohere in a meaningful way or if they clearly differ from each other.

The process of reviewing and refining of the themes at this stage involved two levels. The first level of analysis was at the level of coding data extracts and the second level required review of the entire data set.

At the first level, all extracts collated for a theme were read, and a decision made to determine if the pattern was coherent. If that was the case, we moved to the second level. However, if that was not the case, we looked at the theme, and the data extracted to identify those that were non-fitting. We then created a new theme for the extracts that did not fit into the theme that already existed. If that was not possible, we removed the extract. We moved on to the next level after ensuring that the themes captured the coded data adequately.

We carried out a similar process at the second level. It was also applied to the data set and not just the coded data extracts. The entire data set was read again to check if the themes were applicable representative of the data set, and to code any data in the theme that may have been missed out in the earlier coding process.

The cyclical process of refining and reviewing the themes was an ongoing process that involved noticing new themes and coding for them. This process was stopped when no substantial results in terms of data coding and themes were reached. Themes were then further analysed and combined with the extracts as evidence of the theme, to reveal the story of the data and research.

### 3.5 ETHICAL ISSUES

The study received ethical approval from UCT FHS HREC Reference number 229/2005. This approval was accepted in Botswana for conducting the study.

#### 3.5.1 Benefit/Reward to Participants

No promise of benefit was made. There was no immediate direct benefit to the participating HBCV apart from the possible positive impact of sharing their challenges with someone outside their immediate area of work

#### 3.5.2 Risk to Participants

Confidentiality was maintained. The names of the HBCV or their clients were not documented. There were no identifiers retained for future use. All interviews schedules were kept away securely and analysed later. The supervisors and employees of the clinics were not aware of the identity of the HBCV that consented to give interviews. The HBCVs were informed about these measures taken to protect their identity. The

participants were given the option of choosing convenient places and times for the interview. The interviewers were well-trained personnel with adequate knowledge of family practice principles. They were trained to be alert for any form of distress that may arise during the interview that would result in stopping the interview. No physical or job risk was expected.

### 3.5.3 Informed Consent and Confidentiality/Autonomy

After explanation of the nature and purpose of the study and agreement from the HBCV participants, a written consent was requested.

They were clearly informed that refusal to participate would not in any way affect their remuneration or work in any manner. They were assured that their names would not be recorded or revealed and that complete confidentiality would be maintained. Though the HBCV is all literate in English, the explanation was re-emphasised in the local Tswana language. They were given the chance to ask any pertinent questions and informed they could withdraw from the study at any time they wished.

## **CHAPTER 4.**

### **FINDINGS**

The results of this study are reported in 3 sections as below.

- 4.1 Demographics of participants
- 4.2 Analysis of questionnaires
- 4.3 Thematic analysis of positive and negative attitudes and experiences

#### **4.1 DEMOGRAPHICS OF PARTICIPANTS**

Thirty-three HBC volunteers were involved in this study. The first part of the questionnaire focused on the participants' basic demographic profile - age, sex, marital status, religion and educational level.

The next section explored the participant's knowledge of HIV/AIDS. Identification of opportunistic infections associated with AIDS patient, decisions taken by the participants on being confronted with these conditions and exploration of feelings with regards to caring for or referring AIDS patients.

The findings are presented below. Answers to open-ended questions are expressed in participants own words words.

#### 4.1.1 GENDER OF PARTICIPANTS

Female participants were seven times more than the male participants in the study.

Table 1a: Distribution of Gender of Participants

<b><u>GENDER</u></b>	<b><u>ABSOLUTE NUMBERS</u></b>	<b><u>PERCENTAGES (%)</u></b>
FEMALE	29	88
MALE	4	12

#### 4.1.2 AGE OF PARTICIPANTS

The majority of the participants were between 30 to 39 years of age

Table 1b : Age Range of HBCV

<b><u>AGE (Years)</u></b>	<b><u>ABSOLUTE NUMBERS</u></b>	<b><u>PERCENTAGE(%)</u></b>
Below 20	0	0
20-24	4	12
25-29	4	12
30-34	10	30
35-39	11	34
40-44	3	9
45 and above	1	3
TOTAL	33	100

#### 4.1.3 MARITAL STATUS OF PARTICIPANTS

The majority of participants were single.

Table 2: Marital status of HBCV

<u>MARITAL STATUS</u>	<u>ABSOLUTE NUMBERS</u>	<u>PERCENTAGE(%)</u>
Single	15	46
Married	6	18
Divorced	1	3
Widowed	4	12
Co-habiting	7	21
TOTAL	33	100

#### 4.1.4 RELIGION OF PARTICIPANTS

Most of the participants regarded their religion as Protestant

Table 3: Religions of HBCV

<u>RELIGION</u>	<u>ABSOLUTE NUMBERS</u>	<u>PERCENTAGE(%)</u>
Muslim	0	0
Catholics	5	15
Protestants	24	73
Others	4	12
TOTAL	33	100

#### 4.1.5 EDUCATIONAL LEVEL OF PARTICIPANTS

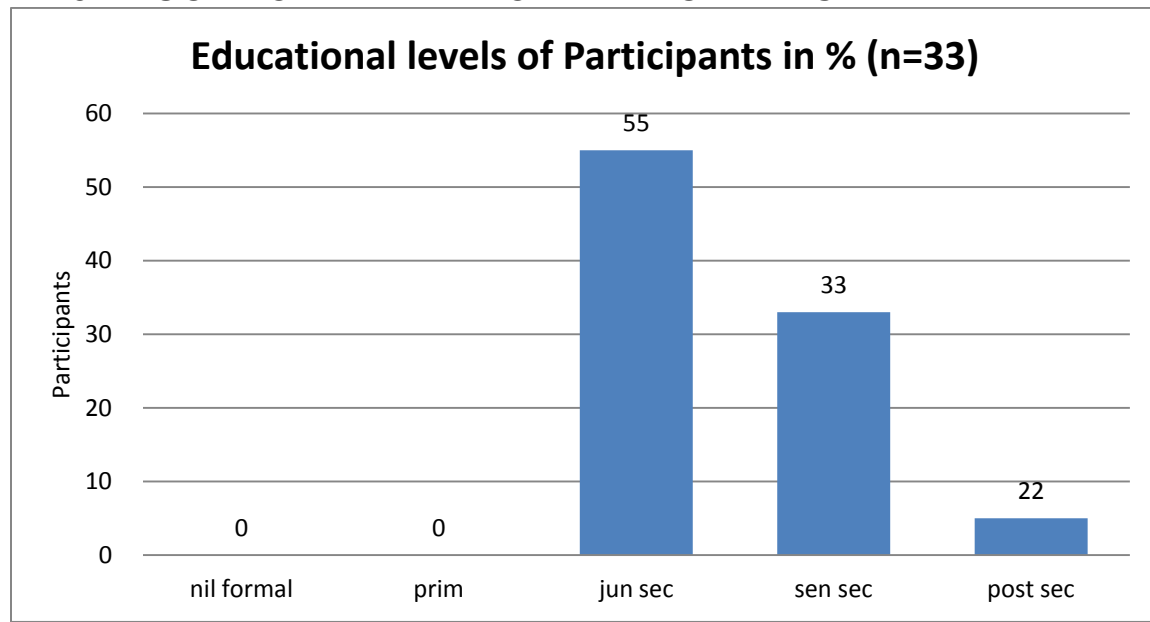


Figure 2: Educational levels of HBCV

Over half of the participants had junior secondary school education.

## 4.2 ANSWERS TO QUESTIONNAIRES

The questions were open-ended, so responses from the participants are arranged in groups. Quotes from the answers provided are used to support the grouping.

### 4.2.1 What are the different ways of getting infected with HIV?

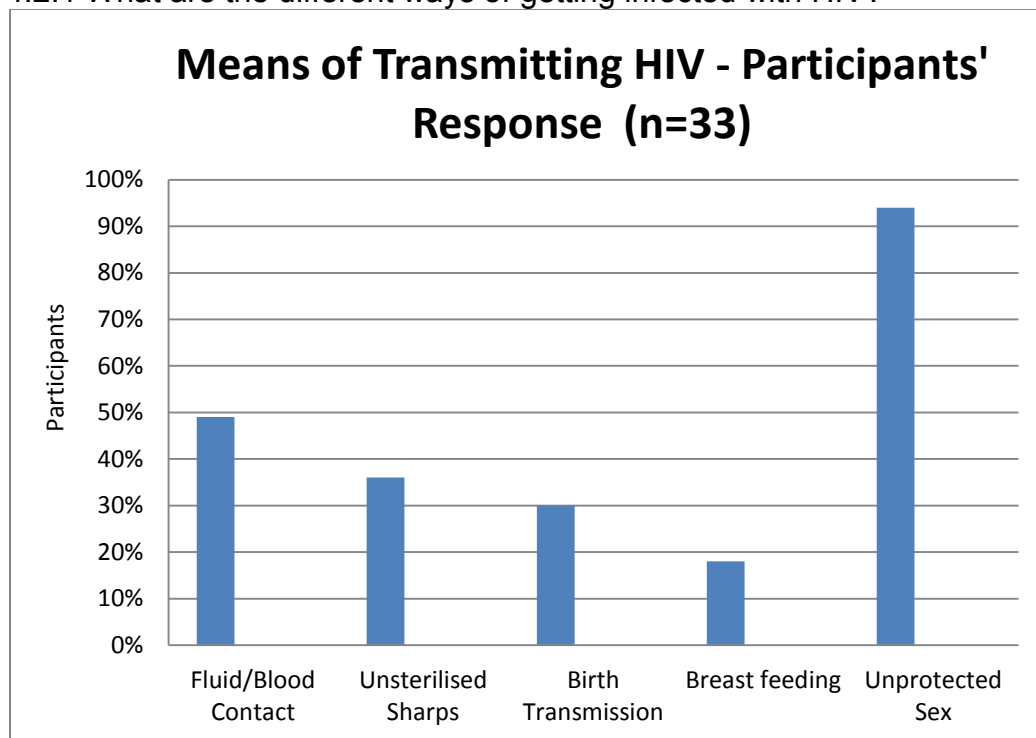


Figure 3: Participants Response to Question on Different Ways of Transmitting HIV

The answers in the participant's words may be grouped as follows

- Unprotected Sex: - 31 of the participants mentioned unprotected sex as a way of getting infected with HIV. This was presented in different ways: Burst condoms, unprotected sex with an infected person, unsafe sex and not using condoms. Most of the participants used the term “unprotected sex” in their answers.

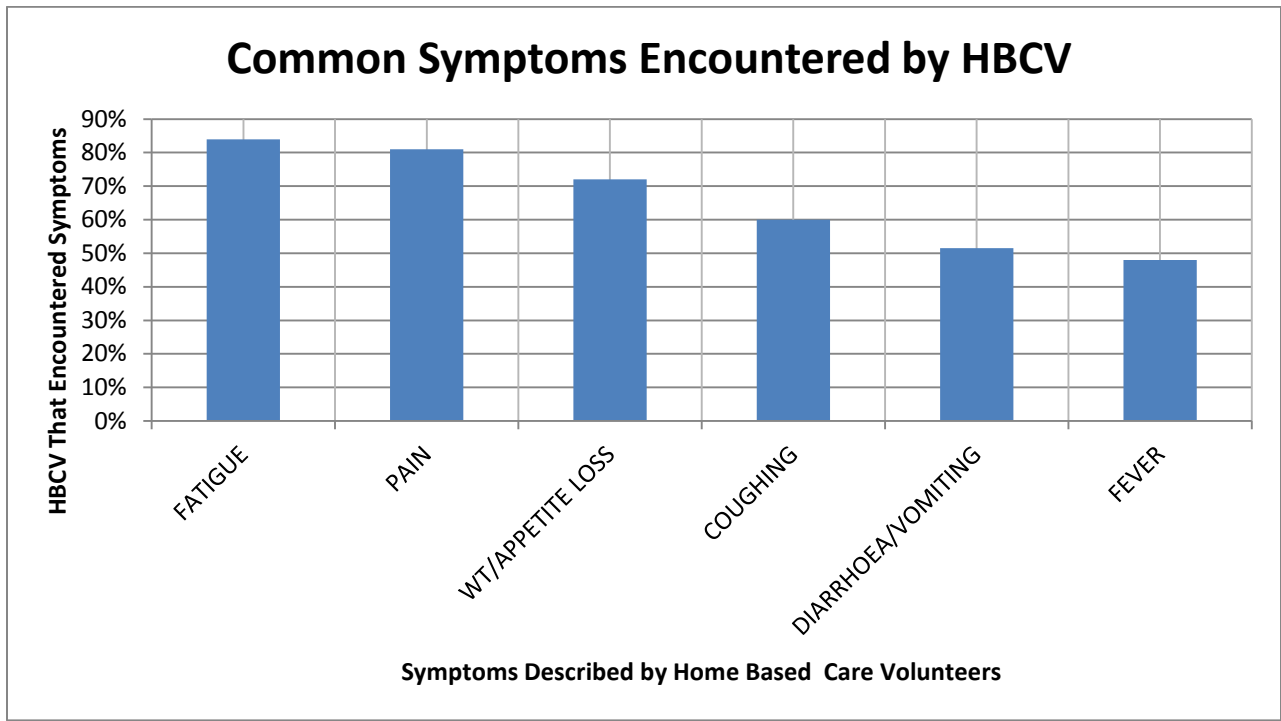
- Fluids / Blood contact – This was mentioned by 16 of the participants as a medium of transmission. Some explained it as “*contact with an infected person’s blood*”, “*handling the injured person who has HIV without using gloves*”, “*body fluid mixing.*”
- Unsterilised needles and sharp objects: Twelve participants mentioned this among the list. Some referred to “*the use of unsterilised needles*” while others referred to the use of “*shaving needles*” and “*razor blades by traditional doctors*”. This was in reference to the traditional practise of cutting the skin with a razor blade.
- Transmission at birth: Ten participants said this was a means of transmitting HIV from mother to child
- Transmission through Breastfeeding: Six of the participants included breastfeeding as a means of transmitting HIV.  

*“By mixing breastfeeding and bottle feeding to the baby.”*
- Blood transfusion: Only four participants included transfusion of HIV-infected blood as a way of transmitting infection. One explained it as “*receiving blood of somebody who is HIV positive*”.

4.2.2 What are the common complaints or ailments you see in your patients?

**TABLE 4: Common Symptoms Encountered by HBCV**

<b><i>Symptoms / Illness</i></b>	<b>(Numbers)</b>	<b>Percentage (%)</b>
Fatigue/weakness	28	84
Pain	27	81
Weight loss / lack of appetite	24	72
Coughing	20	60
Diarrhoea / Vomiting	17	51.5
Fever	16	48



**Figure 4: Common Symptoms Encountered by HBCV**

The participants listed a number of complaints / illness they had encountered from their patients on HBC. The most common of the symptoms /illness are as above.

Other symptoms mentioned include dry mouth, numbness of feet, white spots in the mouth (thrush), and palpitations.

#### 4.2.3 How do you assist your patients with pain?

Table 5: Assistance HBCV would take when HBC patient is in pain

<b>Assistance</b>	<b>Frequency</b>	<b>Percentage (%)</b>
Massaging	20	61
Refer if pain persist	12	36

The participants acknowledged that pain was a common complaint from their patients, especially among those that are “*unable to move themselves from the bed*”. Twenty of them included “*massaging their hands and legs*”. This was found to refer to the upper and lower limbs. Twelve said they would refer the patients to the clinic if the pain persisted. Massaging with a warm compressor seems to be the most popular treatment among the participants. The use of medication is strictly restricted to nurses and doctors. Patients with persistent pain are referred to the doctors for further management.

#### 4.2.4 How do you assist your patients with diarrhoea?

Table 6: Assistance HBCV would take when HBC patient presents with diarrhoea

<b>Assistance</b>	<b>Frequency</b>	<b>Percentage (%)</b>
ORS (Oral Rehydration Solution)	33	100
Refer to clinic if diarrhoea persist	7	21
encourage the patient to take more vegetables	5	15

The participants appeared quite comfortable with this question with all of them mentioning the use of “*salt sugar solution*” or “*ORS*” for treatment. Seven said they would also refer the patient to the clinic for further care. Five mentioned encouraging the patient to take more vegetables in addition to the solution.

#### 4.2.5 What would make you suspect Tuberculosis in your patients?

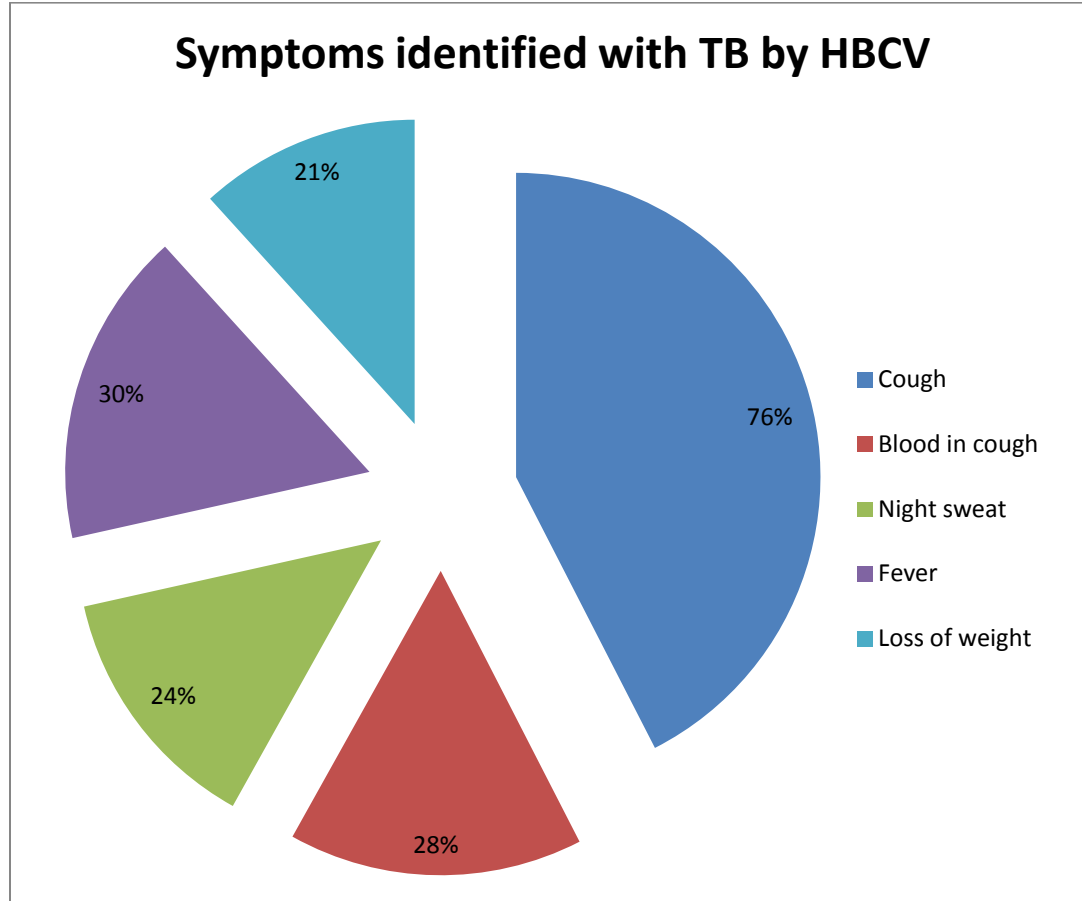


Figure 5: Symptoms associated with TB as identified by HBCV

Twenty-five mentioned cough as the symptoms the patient would present as a complaint. "Blood in the cough" was suggested by nine participants. Eight said night sweat as what would make them suspect TB. One of them referred to his experience with one of the patients he had passed by to see in the evening that was subsequently diagnosed with tuberculosis. He noticed that the patient was "sweating as if he was from the shower". Ten mentioned fever and seven said loss of weight

#### 4.2.6 How would you assist a patient you suspect of having tuberculosis?

All the participants claimed they would refer such a patient immediately to the clinic or the community health nurse in charge of the DOTS program for TB.

The participants' responses to the question enquiring on their level of comfort to referring patients for symptom management is shown below:

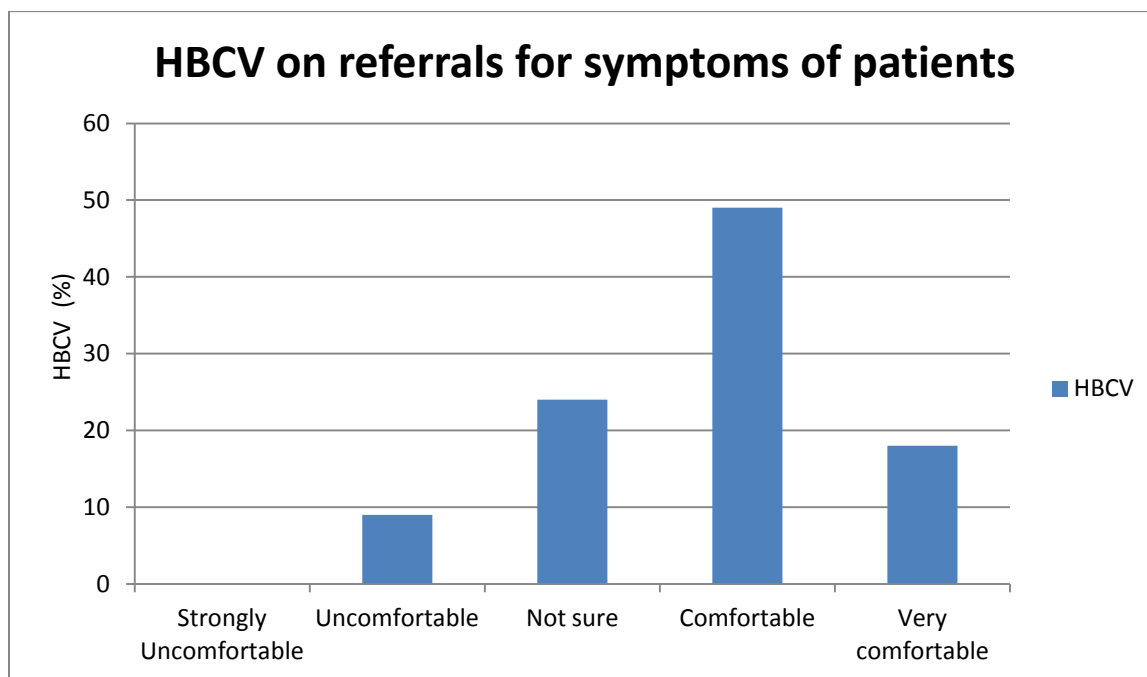


Figure 6 HBCV on referral for symptom management presented by HBC Patients

About half of the participants were comfortable with a referral for symptoms of patients

The HBCV were asked about how comfortable they felt with their work of caring for symptoms presented by their clients.

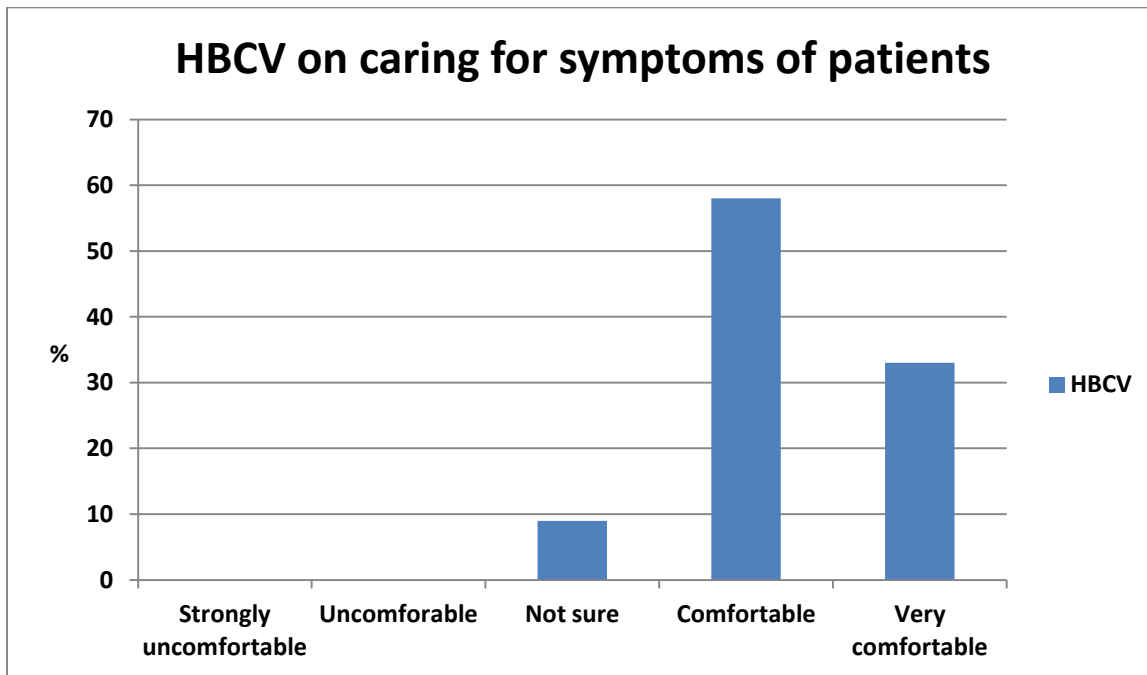


Figure 7 HBCV on caring for symptoms presented by HBC Patients

Over half of the participants were comfortable with caring for symptoms of patients.

### 4.3 PARTICIPANTS' EXPERIENCE ON CARING FOR PATIENTS' SYMPTOMS / CONDITIONS OF HOME BASED CARE PATIENTS

Perceptions of home-based care were analysed, and the themes tabled below emerged.

<b>Theme 1</b> <b>Patient care</b>	<b>Theme 2</b> <b>Family care</b>	<b>Theme 3</b> <b>Community recognition and needs</b>	<b>Theme 4</b> <b>Working with the clinic</b>	<b>Theme 5</b> <b>Personal development &amp; challenges</b>
Pain and symptom control	Appreciation	Public commendation	Referring difficult cases	Skills development
Reduced worry	Dealing with difficult families	Expressions of gratitude	Improved patient care	Acquiring knowledge
Cleaning the house	Discussing patients issues	Maintaining values of Botho	Peace of mind	Spiritual development
Measures to assist patients	Confidentiality		Work with more confidence	Appreciate family better
Grief response			Treatment delays	Improved finances
			Overworked health personnel	Helplessness with patient suffering
			Transport difficulties	

#### 4.3.1 Theme 1 – Patient Care

##### 4.3.1.1 *Pain and symptom control*

Some of the participants mentioned how they involved the clinic in controlling reoccurring vomiting in their patients, who started with the drugs; the patients were taking. These medications were changed by the clinic medical staff resulting in control of the vomiting. They felt “very good” that they were able to help their patients this way.

*“I really feel very good” that I am able to care for my patients by making sure the vomiting stops and the pain is reduced” - P1*

Some said they felt good when they were able to reduce a patient’s pain by massaging and warm compress, even though, the relief is usually only temporary since they cannot give medication to the patient.

*“I feel happy that by using my hands to massage their legs and hand, and using warm compress, I am able to make their pain better...” – P1*

##### 4.3.1.2 *Reduced worry*

Another volunteer mentioned the fear of infection from patients. This worry is reduced with the right use of gloves and protective clothing. P 23 claims that she believes everyone in a hospital is exposed to that possibility and all jobs have their risks.

*“It is something we have always to bear in mind and you find yourself being too careful, not to get a cut or injury at home or work.” P23*

##### 4.3.1.3 *Cleaning the house*

Some participants specifically mentioned the positive feeling they have when they assist some of the patients by tidying the patients' home. In such cases, the patients are usually mothers with young children who are unable to keep the house clean.

*“She had three little children and the house had not been cleaned. It was nice to see her smile again. She said she was worried about the house being so untidy”. – P18*

#### 4.3.1.4 Measures to assist patients

Another source of sadness to some of the HBCV is the neglect and sense of abandonment that some of the patients experience from relatives.

P16 said, *“My patient was a hardworking lady. A beautiful woman. Since this sickness, she is no more the same, and her husband has since abandoned her. He is hardly home. We see him drinking and sleeping around. I wish I could do something immediately. Anyway, the social works officers are now assisting and doing something to help.”* P16

#### 4.3.1.5 Grief Response

Some of the HBCVs say they experience an unpleasant feeling when their patients have to be referred to the hospital by their superiors. It suggests the illness is now beyond these superiors and may lead to death. One of the responses:

*“I sometimes feel a sense of death when some of these patients have to be referred to the hospital. It is usually quite serious. I get this feeling that I may not see this person alive again. It is not easy, especially if you have been looking after this person for some time. You sometimes share jokes, laugh and even cry together. Uum! It is not a pleasant feeling at all.”* – P17

Some of the volunteers claim that they were initially affected by the condition of the patients they had to care for. The images of their sufferings and conditions would remain with them on going home.

*“Sometimes you are at home in the evening, and the cry of suffering of the patient I saw earlier will still be ringing in my ears”.* P22

*“I would be seeing these patients in my mind when I am not with them. This used to disturb me.”* P28

However, she claims she can now get over that and can move on and take care of different patients and handle these thoughts.

#### 4.3.2 Theme 2 – Family Care

##### 4.3.2.1 *Appreciation*

This relates to appreciation shown by the family and patients to the caregivers.

*“The children of this young woman are always so happy to see us. One of them usually stands outside the house and rushes in excitedly to tell others and his mother on sighting us at a distance”. P6*

P3 is talking about a patient who is a child and an orphan. The parents were dead, and she is looked after by an aged grandmother. She said, *“Her grandmother is so old and not strong enough to move around. She is always pouring blessings on us and makes sure she kisses our hand before we leave after attending to her grandchild. She makes you feel so special”*. P3

##### 4.3.2.2 *Dealing with difficult families*

One participant explained her annoyance with a relative of a patient. A drunk young man who was rude to her because he felt they were paid by the government to look after the patients and so should clean and wash the clothes in the house. She said she was quite upset and would have stopped going to that house or stop the job, but the patient and relatives pleaded with her.

*She said, “I almost stopped doing this job that day. He was using abusive language, saying we are paid much money so I must wash all the clothes in the compound and clean his room. He does not even live in the same house with my patient”*. P15

##### 4.3.2.3 *Discussing patients issues*

Answering questions from the relatives and patients regarding the illness was a point of concern to the participants.

*” They sometimes think we know much about their disease, so they ask us questions that we sometimes have no answer,” – P22*

#### 4.3.2.4 Confidentiality

Some of the participants expressed the challenges they face in relation to the issue of confidentiality in the care of their clients

*“We are not even told the illness the patient suffers from and we are not supposed to discuss it even if we know. This is sometimes awkward when they ask us questions they expect us to know. Eish! This can give you stress.”* - P26

The other one said that these patients and their family are

*“Sometimes afraid to ask nurses and doctors questions that feel free to ask us,”* – P10

#### 4.3.3 Theme 3 – Community Recognition and Needs

##### 4.3.3.1 Public commendation

The recognition the job gives them in the community was mentioned.

*“I feel good when I wear my uniform and hat, and people greet me, thanking me for looking after the sick in our community.”* P8

P29 mentioned how she felt appreciated when the pastor in the church she attends requested the congregation to pray for the HBC volunteers. She said:

*“It was nice when the pastor asked God to bless us.... I feel stronger and more willing to do this job. I believe it is a job that God is happy with instead of selling Chibuku.”* -

P29

(Chibuku is a local beer sold in drinking spots. This volunteer told us she had sold chibuku in the past.)

##### 4.3.3.2 Expressions of gratitude

There was an expression of praise for the government for providing support to clients.

One respondent compared their situation with what they had heard from another country:

*"I think our government is trying. I felt proud and lucky to be a Motswana after one of the nurses from a neighbouring country told me how difficult it is for their very sick patient to get assisted with transport and referral, especially if they live in rural areas. The stories she told me of her experiences are really sad. Sometimes these patients suffer and cry in pain in their homes till they die. What kind of government is that? Eish! I do not know how I would have coped if I were working there". – P7*

#### *4.3.3.3 Maintaining values of Botho*

Another volunteer claimed the job of HBC is part of the culture and values of "Botho" in the community, so the community can relate to it. She however went on further to say that the elderly members of the community were more expressive with regards to maintaining the culture of looking after your neighbour in times of need. This is despite the fact that a majority of their patients were the younger populace. She said:

*"Helping each other has always been part of our culture until recently, when people are now concerned only with themselves. It is in the spirit of Botho to assist your sick neighbour and even look after her children when she is sick knowing that somebody will take care of yours if you fall ill. Our elders appreciate this in our work and say our culture as Batswana must not die." - P5*

#### *4.3.3.4 Need for a Hospice*

One of the volunteers, P20, on being asked about negative experiences and feelings, felt that the HBC work is good, but all patients should be kept in one building to receive care and discharged when better. She felt it was not safe enough to leave these ill patients at home where pain cannot be relieved, but *"they should be kept in one place where we can help them all the time."* – P20

#### 4.3.4 Working with the clinic

##### 4.3.4.1 Referring difficult cases

Most of the HBCV were happy about the role of the clinic in helping them in their work.

*“The job is more satisfying when you know that there is somebody or someplace you can get advice if you meet some difficult situation”. – P32*

Some HBCVs felt a sense of failure with referring a patient though they accepted their limitations with managing the patients. One of them felt a strong sense of failure and said:

*“Sometimes I feel sad when I have to refer this patient. It is like I have failed, and I cannot help them. I know I am not a nurse, and I am not supposed to feel that way, but I cannot help my feelings”. – P21*

##### 4.3.4.2 Improved patient care

They felt the referral system gave them a chance to provide better care for their clients.

*“You work happier knowing that you can send your patient to a better place if you get stuck, or the situation is beyond”.*

*“Sometimes their cry is so painful to hear. I thank God that when the massages are no more effective they can benefit from medicines from the clinic”. – P18*

##### 4.3.4.3 Peace of mind

The HBCVs reported that they usually feel a sense of relief and peace of mind on referring their clients when the conditions are beyond their ability to assist. Some of the responses from the participants were:

*“When they eventually come I feel so relieved knowing that I have done the best I can for my patient”. – P27*

*“I feel very helpless when she cries in pain. I get some strength from knowing that even if there is a delay, a person with more knowledge about this sickness will eventually assist her”. – P30*

Some HBCVs expressed their feeling of satisfaction afterwards on seeing the client they had referred. This attitude made them feel they had done the right thing.

*"When their problem is beyond me, and I hand them over to a senior person, I feel good when I next see them and they have improved". - P19*

#### *4.3.4.4 Work with more confidence*

Some of the HBCVs also expressed their happiness that there are such a referral system and the impact on their work, being aware of such a system. P21 said:

*"The fact that there is a system in place that I belong to, that allows me to hand over the patient to a more knowledgeable person, makes me happy and allows me to work with more confidence".- P21*

#### *4.3.4.5 Treatment delays*

The delay with referrals was an issue with some of the HBCVs. They expressed their frustration and helplessness with these delays:

*"It is not a nice feeling when you have somebody in pain in front of you, and you are waiting for assistance. You have done all you can but the pain continues. You know that someone is supposed to help with the relief of this pain, but that person is not there" – P6*

#### *4.3.4.6 Overworked health personnel*

Some participants attributed these delays to their superiors being very busy with other patients:

*"In some cases it takes time for the nurses to visit the patients because they can be very busy at the clinic". – P15*

Some feel that the health personnel are overworked with too many patients to care for, leading to delays in referrals.

*"It is not easy for them to always be available. They are overworked and sometimes too tired. We need more of the qualified people to assist with serious conditions". P19*

#### 4.3.4.7 Transport difficulties

Delay due to unavailability of transport, sometimes to take the patient who may need admission to the hospital was also mentioned as a source of frustration.

*"It can be very frustrating when the patients need transport from home to be referred to the clinic or hospital and it is not available. Sometimes their pain can be so much despite all the massaging you can do, that you wish you could even carry them on your back". – P19*

Some think that the difficulty with transport of patients is because the vehicles have multiple uses.

*"These vehicles are used for other things apart from transporting these patients, so they may not be available immediately when needed." P18*

#### 4.3.5 Personal Development & Challenges

##### 4.3.5.1 Skills development

Some participants felt they had learnt more about the human body and developed more skills.

*What I have learnt about the human being in this job, I tell you regular school would not have taught me. I understand the human body so much better. The human body can be so strong, resisting much, but in some situation, it can be so fragile". P11*

*"I have learnt more, and improved my skills of caring for very sick people" – P30*

##### 4.3.5.2 Acquiring knowledge

Some of the participants felt their work had exposed them, making them more knowledgeable.

*"Eish! This my work is like going to a school of life. It has made me wiser and to see life in a different way. I am able to see the different challenges people are facing in our community. It is amazing the things that are happening behind the walls of these houses people pass by daily. If people knew, many would be wiser." P10*

#### 4.3.5.3 Spiritual development

Some of the participants' statements underline the impact of religion and spiritual beliefs on the HBCVs as they carried out their duties. Some of them looked at their duties beyond that of a usual job and more of a spiritual duty to their fellow human beings.

*"this is what the Bible says we should do. As a Christian, I believe it is my duty to assist the needy in my community". P12*

Some others said they had been involved in similar activities through their churches and spiritual organisations. For some their duties as HBCV has instigated them to develop a closer relationship with God.

*"I have learned a lot of this work. Seeing people so sick and possibly dying has made me seek God more, and I am a better person". P4*

For others, their job has helped to reassure them about the presence and good work of God:

*"You may not believe this but I tell you, many of my patients always feel stronger and better the next day after we discuss God and pray together. This tells me I am doing the right thing and reminds me that God has not forgotten us". – P14*

One of the HBCVs said her works allowed her to develop herself in spreading the words of God, especially to the sick who feel hopeless as AIDS is not a curable disease:

*"We are continuously reminded that AIDS has no cure. So the ARV is just to prolong your life. God is the only hope left. I always tell my patient to trust in God in whatever situation they find themselves and understand that he has forgiven them for their sins".*

– P23

#### 4.3.5.4 Appreciate family better

Some said they had learnt a lot from their experience as HBCV. They said they had learnt not only how to care for sick people, but their daily activities with them have taught them to look at life differently.

*"This job has made me appreciate my life and my family better. Another said, "I am a better mother and wife because of what I see every day. When I get home, I thank God for my healthy children and husband." P17*

Two of the participants expressed their sadness on leaving the young children of some of their young patients when they have to leave.

*"it leaves a very sad feeling in my stomach when I look at the eyes of those young children as I leave. They make me think of my children, and I cannot help imagining my kids in their position." P18*

This particular participant is a widow with three children.

#### 4.3.5.5 Improved finances

They appreciate the payout by the government to the HBCVs. For some, it was not an important factor in their decision to perform HBC, but a welcome and useful income to assist in meeting their needs.

*"I enjoy this job looking after sick people in my area. I would have done it for free as I know some of these people. This government paying us for this is a great thing as it means I can look after myself and my children better". P3*

For P13, it was the sole source of income after a period of joblessness:

*"Since I completed school, I have not been able to get a job. At least I can now look after myself with what I am paid". P13*

P20 saw the income as little but additional revenue for the family:

*"We are not paid much but it is enough to help me contribute to the household income. I can bring something home every month to add to my husband's income" P20*

#### *4.3.5.6 Helplessness with patient suffering*

Some of the participants mentioned the helplessness they feel with pain control. Though they are comfortable with doing their jobs, they do sometimes feel helpless when they are unable to control suffering with their level of intervention.

*“I feel sad, when I am unable to do much for the pain they feel.” P33*

*“I feel very helpless when she cries so much from the pain and all she has is the paracetamol she was given at the clinic, which she has already been taking.” P4*

*“we sometimes massage them, but we know that is only temporary relief With the severity of pain and discomfort, you feel sad and helpless knowing that this massaging cannot do much and that the patient needs stronger medication. It is terrible to suffer in pain both for the patient and those caring for the patient.” P9*

Some claim the pain is hard to pinpoint, and the patient just complains of pain.

*“Even if I massage her, or she takes the medicine she would still complain of pain. It appears to be all over the bones.” – P26*

*“The patients’ suffering can make you feel useless”. P15*

The participants said they usually refer such patients to the clinic for further assistance with medications.

This chapter reported on the findings of this research. It dissected the demography of the participants, revealing their different characteristics groups. It further reported on their responses to direct questions presented during the study. The report analysed inductively and deductively the positive and negative attitudes, and experiences of the HBCV. It related these to their work of caring for the symptoms and referrals of the patients. It qualitatively identified, analysed and reported patterns as presented in the collected data from the participants for further care, perception of the participating home based care givers, using thematic analysis.

## CHAPTER 5.

### DISCUSSION

A number of studies have been conducted in the past with regards to home based care for PLHIV (Shaibu 2006; Fako and Gary Linn 2006; Oner 2005; Kalubuzi 2005; Katapa 2004; Mbata- Ndaba and Seloilwe 2000). However, the researcher in this present study did not come across studies specifically on the knowledge and experiences of home-based care volunteers (HBCV) in relation to diagnosis, managing and referrals of common symptoms presented to them by PLHIV in their daily care activities. There is little published research assessing the knowledge of HBCV even though these are the people who are usually in daily contact with PLHIV.

The demographics in this study revealed that the majority of the HBCV were female. This findings is similar to other studies in the past that reflected female carers as caregivers for terminally ill patients ( Mbata- Ndaba 1998; Emmanuel et al 1999; Lindsey et al 2000; Boon et al 2009). This role of caring, played by female members of the family or community has been part of the Botswana tradition and in most countries in Africa.

The findings of this study revealed that the minimal education of volunteers was at the junior secondary school level. With the responsibility that comes with being a HBCV and being involved in the care of PLHIV, this level of formal education could be seen as a positive factor in training for the HBCV role. Previously HBC was mainly provided by family members, and usually older women and grandmothers with little or no formal education (Boon et al 2009) and no HBC training. Less than 25% of the HBCV were below thirty years of age, and as shown above mainly women. It is likely that most of these HBCVs volunteers in addition to their HBCV roles had other major activities and tasks in their own homes that may negatively affect their ability to continue or focus on schooling. An appropriate adult education programme may play a positive role. The

HBCVs answers regarding knowledge HIV/AIDS showed different responses. There is minimal literature assessing HBCV knowledge of HIV/AIDS. However, the findings of this study were similar to that of a study carried out in neighbouring Namibia (Niikondo, Hoque and Ntuli-Ngcobo 2011). The researchers in their assessment of HBCV knowledge of HIV/AIDS and ART in Namibia, found out that the knowledge was above average in some aspects while lacking in other aspects. The HBCV are expected to have basic knowledge of HIV/AIDS with regards to transmission, prevention of infection, expected symptoms related to AIDS and treatment support.

This study showed that fatigue/ weakness and pain were the symptoms most identified by the HBCV. Pain is a major palliative care symptom and has been found one of the reported symptoms in PLHIV as revealed in earlier and recent studies (Hewith et al 1997; Rosenfeld et al 1999; Tsai, Hsiung and Holzemer 2002; Parker, Stein and Jelsma 2014). The high prevalence of pain, as recognized by the HBCV, is in keeping with other studies among HIV/AIDS patients (Tran et al 2011; Norval 2004.) However, this is in contrast to some other studies showing lower prevalence of pain among ambulatory PLWHA (Tran et al 2011) describing a pain prevalence of 10.9. it appears that the PLHIV described by Tran et al had not deteriorated enough to require home based care. In terms of symptoms of pain among PLHIV, the prevalence as shown by the identification of such patients by HBCV, would be similar to that reflected by Navasimooloo, Naidoo and Gaede. In their study of HIV positive in-patients at an urban hospital in KwaZulu Natal, South Africa, 91% of these patients reported pain as a primary symptom.

The HBCV was usually the first among the team to encounter patients with the symptoms of pain. They applied different ways to soothe or reduce pain among PLHIV as they were unable to prescribe medications for pain. Massaging with a warm compress was the most used intervention by them. Others would refer the patient to the clinics. The approach of massage and warm compress application was similar to the pain intervention by health care providers in Taiwan. They also used massage and “cover with a hot pack” as a means of managing pain symptoms among PLHIV (Tsai et al 2002). The massage of painful limbs and warm compresses was an option that was

soothing and easy to perform, though not on the level of opioids for AIDS-associated pain relief. Due to the process involved with prescription of opioids, many patients in need of opioids suffer unnecessarily before getting medication for relief. This is highlighted by the opioid phobia that is still quite prevalent and high among most health personnel. The massage and warm compressors may help by reducing the sensation of pain, but at a relatively minimal level in comparison with opioids. It would likely be inadequate if used alone for pain experienced by PLHIV. The PLHIV in this study, reportedly felt pain in different parts of the body and limbs. The multiple pain sites would suggest that there are possibly different pathological processes causing pain at a particular time. This underlines the importance and complexity of pain among PLHIV, and the challenges and frustrations faced by HBCVs as they encounter these cases on a daily basis. A significant finding of this research is that pain is a major undertreated complaint by PLHIV.

All the HBCVs in the current study mentioned the use of oral rehydration therapy (ORT) for the management of diarrhoea. Diarrhoea is one of the common symptoms of PLHIV in Botswana. The HBCVs appeared quite comfortable with its management. This may be because management of diarrhoea with easily prepared oral rehydration therapy is a major topic in public health education. Mothers in particular were encouraged to be conversant with the use of ORT, in the management of diarrhoea among children. The under five cards for children are readily available and have illustrated explanation on the use of salt, sugar, and boiled water as the main ingredients for oral rehydration therapy. The explanation is in the local Setswana and English. The information is also repeatedly broadcasted in different types of media for the general public. ORT is thus readily accepted and used for diarrhoea management in Botswana. This is a bit different from the findings of Tsai et al (2002) in Taiwan where the management of diarrhea among PLHIV did not include the use of ORT. The participants in Tsai et al (2002) study mentioned the eating of vegetables and fruits, taking anti-diarrhoeal drugs, drinking more water and enduring the diarrhoea as the different ways diarrhoea is managed. With the emphasis on ORT as the major intervention in diarrhoea as recommended by the World Health Organisation (WHO), the HBCVs are relatively equipped to manage diarrhoea among patients in Botswana.

However, the participants in Tsai et al (2002) research reported they would send patients to the Emergency room or OPD as additional measures for the diarrhoea. This is similar to the extra actions by some of the HBCVs in this current research who said they would refer the PLHIV if the diarrhoea persisted.

Tuberculosis(TB) is highly prevalent among PLHIV. PLHIV are 26-31 times more likely to develop TB as compared to persons without HIV (WHO 2014). It is also the leading cause of death among PLHIV, and at least one-third of the 35 million people living with HIV worldwide are infected with latent TB. The HBCVs recognised that one of the symptoms of TB is cough, with a few mentioning blood in the sputum and night sweat as symptoms of TB. Pulmonary TB patients usually present with cough as a major presentation and may have haemoptysis, loss of weight, and night sweats as other possible symptoms. The HBCVs seem able to suspect tuberculosis among PLHIV and recognised the need for referral. The ability of HBCVs in identifying TB among the PLHIV they care for, would result in early intervention that should lead to lower morbidity and mortality. The impact of the knowledge of these symptoms would also be of preventive and community health significance as the PLHIV reside within the community. The HBCVs in their regular visit to their clients, may be able to identify these symptoms not only among PLHIV but also among other members of the family and community.

The response of the HBCVs in this current study further emphasises this point. All the participating HBCVs said they would refer patients presenting with these symptoms suggestive of TB to the clinic, or community health nurse in charge of the directly observed therapy (DOT) program for TB, in their community.

As regular and frontline carers for PLHIV, It is important that they be able to identify conditions beyond their capacity and refer appropriately. There use of the referral system is supported by the responses from all the HBCVs in this study, that they would refer PLHIV presenting with symptoms suggestive of TB.

The care and referrals of the PLHIV can be a challenge for any carer or health personnel. Most of the participants in this study were comfortable or very comfortable

with taking on the role of referring PLHIV. With their limited medical knowledge, this suggests that they most likely have a good communication relationship with the receiving health personnel or facilities.

The referral system is a significant part of part of home based care to ensure continuity of care. These referrals are essential for adequate communication and feedback between the different levels of care. Lack of this communication between hospitals, clinics, and the HBCVs would result in delayed or no relief for the PLHIV.

The consequences of poor or lack of referrals are multiple. The PLHIV would not receive appropriate and timely assistance for pain and other ailment, and this would worsen their condition. There would be less trust and confidence in government health programmes and facilities. The PLHIV would source alternative and sometimes dangerous source of comfort for their pain and ailment. All of these may likely result in an increase in morbidity and mortality among PLHIV.

A number of positive and negative issues were associated with the experiences of HBCVs, as they carry out the tasks of caring for the PLHIV.

This study highlighted issues regarding the responses of family members of PLHIV. The HBCVs felt encouraged by the appreciation expressed by the relations of PLHIV. However, there were cases where family relations expect more than what the HBCVs were mandated to do. As shown in the demography of HBCVs most of them are women and may be exposed to abuse (Orner 2007). These would have some demotivating effect on the HBCVs and increase their stress in an already stressful work. Most of the health workers particularly those involved in caring for palliative patients are exposed to unique stressors. These may lead to fatigue that may ultimately result in reduced care for their clients and themselves. This is supported by other studies that have shown that caring for PLHIV result in more severe and sharper burnout than in other areas of healthcare (Bellani et al,1996). These negative experiences are associated with the stigma and discrimination faced by PLHIV and their carers, due to the ignorance of people in the community (Ditsheko 2006). Increased public awareness about HIV/AIDS and the activities of HBCVs may help to reduce such discriminations. It

is a well known fact that such discriminations affects access to social interaction and support (Carr and Gramling, 2004).

The HBCVs in this study experienced pleasant, positive feelings with the improvement of their clients position after their contributions that may include the use of massage or referral. The resultant feel good experienced after referral was a motivating positive feeling among HBCVs and encouraged them to take decisive action for the clients. In contrast, the sense of helplessness and sadness felt by the HBCVs while nursing the PLHIV with severe pain may counter this positive feeling. In such cases, all the HBCV was able to do was to massage their limbs, working towards pain reduction. This intervention is usually insufficient to control severe pain, and such a client would need to be referred. The availability of such referral services is highly supportive and motivating for the HBCV.

A number of HBCVs were affected religiously or spiritually. Religion and spirituality both have a sense of transcendence. However, Spirituality has been reported as made up of three parts - nature, divine wisdom from a high power, and the self (Chandler 2013). Religion is more institutionalised as practised in Botswana and most other communities. The responses from HBCVs described their care of PLHIV as drawing some closer to God, reassured some about presence of God, helped to develop themselves in spreading word of God and strengthening their practice in the African culture of "Botho".

In contrast, some of the HBCVs helplessly witness the persistent pain of PLHIV. The memory of such pain and sometimes hopelessness remains with these HBCVs long after the end of the work day as described by Bellani et al. In addition, the fear of possible infection is ever present in their minds as they closely nurse these patients, massaging them. It is expected that this would result in increased stress and the need for psychological and emotional support through counselling. Counselling of carers has been mentioned in the past as an important part of care (Ncube and Munodawafa, 1997).

The HBCVs need to receive counselling continuously as a coping strategy for these stresses they encounter in their daily work. The fear of being infected is a primary

concern among carers of PLHIV (Maneesriwongul et al, 2004). This further underlines the significance of providing counselling regularly for the HBCVs.

### LIMITATIONS OF THE STUDY

The data used in this project was based on responses generated by the HBCVs. These are self generated responses and may have been influenced by the sensitivity of the topic which is related to caring for PLHIV. The HBC programme is a national programme but the participants in this study were from a particular part of Botswana, so they may have peculiar or different characteristics and challenges from other HBC programmes. These factors may have an effect on the findings and deductions from this study.

There were 33 participants in this study. This is a small sample size for most research. However, this is a study, in which the participants specifically have to be HBCVs, thus limiting the sample size. There may be a need in the future to conduct a broader study among HBCVs across Botswana, to involve a larger number of participants to explore further issues generated from this study.

### IN SUMMARY

The study of HBCVs knowledge and experiences with regards to caring and referrals of PLHIV has been relatively unexplored. This study has attempted to extend the present understanding within the context of HIV/AIDS and palliative care.

From the findings of this study, we see the need for significant support and counselling for HBCVs, to assist them deal with the negative psychological and emotional outcomes of their daily work. If this support is unavailable, the HBC programme may not be successful as it is dependent on the activities of the HBCVs who are usually part of the community.

Most of the HBCVs in this research were reasonably knowledgeable about HIV/AIDS. There should be continuous updating and fortification of their knowledge to empower

and enable them to continue operating in the forefront of home based care and the application of basic palliative care for PLHIV.

This study revealed the multiple issues the HBCVs have to deal with by their exposures to very ill and suffering clients. Most of these HBCVs have not been through a previous nursing, paramedical or medical training. They may not be fully prepared for the level of suffering or pain their client's exhibit. They need to be developed and trained for what they would encounter in the HBC programme. In addition, they may be exposed to possible stress, burnout and other potential mental health issues. These HBCVs would need to have periods of substantial breaks, debriefing and expert psychological care. It would be motivating to encourage them and for the community to recognize them for their jobs, in different ways. This may help to reduce any possible stigma and discrimination associated with their work.

From this study, it is seen that the HBCVs are appreciated as they carry out their caring and referral activities. It may be enlightening to explore other issues that would motivate the HBCVs in performing their activities.

This study showed the importance of spiritual development to the PLHIV and HBCVs. This further emphasises the importance of extending care beyond the physical needs of the PLHIV to include a more holistic approach. A bio-psychosocial approach would better meet the multiple needs of the PLHIV and HBCVs. The programme should include these factors in the training of HBCVs and the management of PLHIV.

A major emphasis by the participating HBCVs is the issue of helplessness in control of pain and the severity of pain suffered by PLHIV. This points to the global issue of opioid phobia among health care providers. There should be more palliative care awareness in the training of all health professionals towards the control of pain among PLHIV and other patients. This training should be initiated early in their trainings, and practiced readily to enable the prompt availability and accessibility of patients to opioids in a responsible manner that would prevent avoidable suffering and pain.

Necessary referrals of PLHIV with pain and other illness should follow an easy algorithm which would involve quick identification and assessment of pain and other symptoms. The control of pain should be initiated early. The referral system should be

smoother with more vehicles and personnel involved for prompt movement of these patients in need of referrals.

In this conclusion, it is important to also note that the HBCVs were very appreciative of the effort of the Botswana government to train them, provide an income for them and empower them to play a role in the care of PLHIV. However, they feel that there is more that can be done to make the HBC programme more viable and productive towards caring for PLHIV.

#### Benefit to Policymakers & HBC groups

Though there are ethical concerns with this study, we should also note that in terms of *beneficence*, it may also help with improving care for patients receiving home-based care. It may be useful in influencing palliative care policies of the government of Botswana who has shown great interest by including home based care as a formal government programme.

The deductions from this study will assist decision makers and HBC groups to understand the challenges and achievements faced with the present HBC programs. They would be better equipped to review the current situation and put necessary measures in place to address them.

## CONCLUSION AND RECOMMENDATIONS

The above findings and discussions indicates that most of the study objectives have been met.

The demographic distribution of the HBCVs in the sample population was determined. The HBCVs revealed their knowledge and perceptions of the common symptoms associated with AIDS in Botswana. These were in relation to the diagnosis of HIV, the presentation of these symptoms, and the necessary measures to alleviate these symptoms at their level. The findings also revealed issues and challenges associated with the referrals of these patients, when the management of their symptoms and conditions are beyond the HBCVs.

### Recommendations

The recommendations arising from this studies are as follows:

- A continuous training and education programme be put in place to update and refresh HBCVs knowledge of HIV/AIDS and associated issues. They are in many cases the first contact with PLHIV when they experience the symptoms associated with HIV/AIDS.
- A readily accessible and available HBCV focused support and counselling service for the HBCVs to assist in the management of the different unfamiliar psychological and emotional outcomes associated with their HBC activities
- Chiefs, headmen, and community leaders of local communities to be made aware of the defined roles of HBCVs and boundaries of their activities.
- Initiation of community local awareness programmes through the Kgotlas (Community/Tribal meeting place controlled by the chiefs and headmen) to enlighten the communities on HBCVs activities.
- Address Opiophobia among clinicians and supervisors of HBCVs through targeted training to correct unfounded misconceptions and fears that impede prompt and necessary treatment with opioid analgesia.
- Review and strengthening the referral system with adequate vehicles and personnel to facilitate the prompt handover of PLHIV.

## REFERENCES:

- Anastasi, A. (. (1998). *Psychological testing*. New York: Macmillan.
- Atkinson, J. G. ( 1988). Prevalence of psychiatric disorders among men infected with human immunodeficiency virus. *Arch General Psychiatry*, 45: 859–864.
- Bellani, M. (1996). Burnout and related factors among HIV health care workers. . *AIDS Care* , 8(2): 207-21.
- BIDPA. (2000). *Macro-economic impacts of the HIV/AIDS epidemic in Botswana*. Gaborone: Botswana Institute for Development Policy Analysis / UNDP/Government of Botswana.
- Bonnel, R. (2000). *HIV/AIDS: Does it increase or decrease growth in Africa?* . Washington DC: World Bank. .
- Boon H, R. R. (2009). The impact of a community-based pilot health education intervention for older people as caregivers of orphaned and sick children as a result of HIV and AIDS in South Africa. *J.Cross Cult Gerontol*, 373-89.
- Breibart H, R. B. (1996). Breibart H, Rosenfeld BD, McDonThe undertreatment of pain in ambulatory AIDS patients. *Pain*, 65:243-249.
- Breibart H, P. S. (1996). Pain in AIDS: a call for action. *Pain Clin Updates*, IV:1–8.
- Brink, P. &. ( 1994). *Advanced design in nursing research*. Thousand Oaks,CA: Sage.
- Calabrese, L. H., Kelley, D. M., Cullen, R. J., & Locker, G. (06/1991). Physicians' attitudes, beliefs, and practices regarding AIDS health care promotion. *Arch Intern Med*, 1157.
- Carr, G. &. (2004). Stigma: health barrier for women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care.*, 15(5): 30-9.
- Chandler, Siobhan. 2013. “Way of the Spiritual Seeker: As Above So Below.” In ed. D. Bryant, *Ways of the Spirit*, 176-183. Pandora: Kitchener
- Chuang, H. D. (1989). Psychosocial distress and well-being among gay and bisexual men with human immunodeficiency virus infection. *Am J Psychiatry*, 146: 876–880.
- Ditsheko AN (2006). *HIV/AIDS clients and their caregivers’ perceptions of a community home-based care support programme in botswana: a qualitative study*. Thesis submitted in partial fulfilment of the requirements for the degree of Masters In Public Health Fac Health Sci, School Of Public Health & Family Medicine University Of CapeTown
- Duffy T, M. C. ( 2000). Health visitor’s knowledge and attitude relating to HIV and AIDS. *Community Nurse* , 422, 424, 426-30.
- Els, R., & Power, H. (2006). Morphine use in the last six days of life of patients with HIV/AIDS at the inpatient unit of a South African hospice implementing the ICHC model. *South African Family Practice*, Volume 48, Issue 4.
- Epstein BG ( 2004). *The demographic impact of HIV/AIDS*. . Washington (D.C):. The demographic impact of HIV/AIDS. In: Hacker M, editor. International Monetary Fund.
- Fantoni, M. R. (1997). Multicentre study on the prevalence of symptoms and symptomatic treatment. *J Palliative Care.*, 13: 9–13.
- Fontaine, A. L. (1999). Physicians' recognition of the symptoms experienced by HIV patients (How reliable?) . *J Pain Symptom Manage*. 1999; , 13: 263–270.
- G., L. ( 2003 ). Prevalence of and factors associated with HIV/AIDS related stigma and discriminatory attitudes in Botswana. *J Health Popul Nutr.* , (4): 347-57.

- Gebbie, K. (1995). A holistic look at the human immunodeficiency virus pandemic. *Holistic Nursing Prac*, 10: 1–9.
- Gir E, R. P. (2001). Changes in life style needs and difficulties faced by caregivers of AIDS patients in home care. *J Nurs*, 35(4): 328-35.
- Government of Botswana Central Statistics Office. (2011). Retrieved from Botswana Housing and Population Census 2011: [www.cso.gov.bw/images/analytical\\_report.pdf](http://www.cso.gov.bw/images/analytical_report.pdf)
- Ministry of Health (Botswana). (2008). *HIV/AIDS Treatment Guideline*. Botswana : Available from [www.moh.gov.bw/Publications/HIVAIDS%20TREATMENT%20GUIDELINES.pdf](http://www.moh.gov.bw/Publications/HIVAIDS%20TREATMENT%20GUIDELINES.pdf) accessed 25 August 2015
- Gwyther L, M. A. (2006.). *A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa*. Kampala, Uganda: : APCA.
- Hegyvary, S. (1993). Issues in outcomes research. *J Nurs Quality Assur*, 5: 1–6.
- Holzemer WL. (2002). HIV and AIDS. *the symptom experience. What cell counts and viral loads won't tell you.*, 102: 48-52.
- Hsiung, P. T. (2000). Factors in psychiatric distress of patients with AIDS. *Formosan J Med*, 4: 398–406.
- JA, J. T. (2008). Clinical pain management. *chronic pain*, 352–61.
- Jackson, H., & Kerkhoven, R. (1995). Developing AIDS care in Zimbabwe: a case for residential community centres? *AIDS care*, Volume 7, Issue 5. (July-August 2000). *American Journal of Hospice and Palliative Care* .
- Larue, F. B. (1994). Pain and symptoms in HIV disease. *J Palliat Care*, 10: 95. Larue, F., Brasseur, L., Musseault, P., Demeulemeester, R., Bonifassi, L., and Bez, G. Pa (a national survey in France (abstract)) . *J Palliat Care*, 10: 95.
- Makoe, L. N., Seboni, N. M., & Molosiwa, K. (05/2005). The symptom experience of people living with HIV/AIDS in Southern Africa . *The Journal of the Association of Nurses in AIDS Care : JANAC*, Volume 16, Issue 3.
- Maneesriwongul, W., Panutat, S., Putwatana, P., Srirapo-ngam, Y., Ounprasertpong, L., & Williams, A. B. (05/2004). Educational needs of family caregivers of persons living with HIV/AIDS in Thailand . *The Journal of the Association of Nurses in AIDS Care : JANAC*, Volume 15, Issue 3.
- Ministry of Health (Botswana), 2005, *Botswana national HIV/AIDS treatment guidelines*, Government Printer, Gaborone.
- Ministry of Health (Botswana), (1997). *Botswana HIV and AIDS Second Medium Term Plan MTP 1997-2002*. Gaborone: AIDS/STD Unit, Ministry of Health.
- Mogae, F. G. (2000). Botswana's president: "our people are crying out for help". *J AIDS Pol & Law*, 15(18): 13.
- Patton, M. Q. (2001). *Qualitative evaluation and research methods* (3rd ed.). Newbury Park, CA: Sage Publications.
- World Bank. (2000). *HIV/AIDS: Does it increase or decrease growth in Africa?* Washington DC: World Bank.
- Rajaraman, D., Russell, S., & Heyman, J. (October 2006). Rajaraman D, Russell S, Heyman J. HIV/AIDS, income loss and economic survival in Botswana. *AIDS Case*, 18(7):656-662.

Rice, C. (2008). *HIV and AIDS*. Wilson PR, Watson PJ: Haythornthwaite. UNAIDS 2014 Report on the Global AIDS Epidemic Update. Available at [www.unaids.org/sites/default/files/media\\_asset/GARPR\\_2014\\_guidelines\\_en\\_0.pdf](http://www.unaids.org/sites/default/files/media_asset/GARPR_2014_guidelines_en_0.pdf) accessed 30 September 2015

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life  
World Bank. (2000). *HIV/AIDS: Does it increase or decrease growth in Africa?* Washington

DC: World Bank. Available at [Worldbank.org/INTAFRREGTOPHIVAIDS/.../Growth\\_in\\_Africa.pdf](http://Worldbank.org/INTAFRREGTOPHIVAIDS/.../Growth_in_Africa.pdf)

Zeller, J. M., Swanson, B., & Cohen, F. L. (1993). Suggestions for clinical nursing research  
(Symptom management in AIDS patients). *J Assoc Nurses AIDS Care*, 4: 13–17.

Zimba, E. W., & Mc Inerney, P. A. (2001 Aug). The knowledge and practices of primary care  
givers regarding home based care of HIV/AIDS children in Blantyre(Malawi)...;  
*Curationis*, 24(3): 83-91.

## **APPENDIX A**

### **QUESTIONNAIRE**

TO DETERMINE HBC VOLUNTEERS' KNOWLEDGE ATTITUDE AND PERCEPTION OF DIAGNOSIS, TREATMENT AND REFERRAL OF COMMON SYMPTOMS ASSOCIATED WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) IN BOTSWANA)

- 1) AGE .....(Years)
  
- 2) SEX: Male..... Female.....
  
- 3) MARITAL STATUS:
  - a) Single..... b) Married..... c) Divorced..... d) Widowed.....
  - e) Co-habiting.....
  
- 4) RELIGION:
  - a) Moslem..... b) Catholics..... c) Non- Catholic Christians.....
  - d) Others.....
  
- 5) EDUCATIONAL LEVEL:
  - a) Primary..... b)Jun.Sec. .... c) Sen. Sec.....d)Degree...
  - e) No Formal Education.....
  
- 7) WHAT ARE THE DIFFERENT WAYS TO GET HIV/AIDS:
  
  
- 8) WHAT COMMON SYMPTOMS DO YOU SEE WITH YOUR PATIENTS WITH AIDS:
  
  
- 9) HOW DO YOU ASSIST YOUR PATIENTS WITH PAIN?

10) WHAT IS YOUR EXPERIENCE WITH REFERRALS OF PATIENTS

11) WHAT WOULD MAKE YOU SUSPECT TUBERCULOSIS IN YOUR PATIENTS?

12) HOW WOULD YOU ASSIST A PATIENT YOU SUSPECT OF HAVING TUBERCULOSIS?

13) WHAT DO YOU DO FOR YOUR PATIENT PASSING FREQUENT AND WATERY STOOLS :

14) WHEN DO YOU REFER SUCH A PATIENT?

15) HOW DO YOU PROTECT YOURSELF FROM GETTING HIV WHILE HELPING YOUR PATIENT

16) HOW WOULD YOU RATE YOUR LEVEL OF COMFORT WITH REFERRING PATIENTS FOR MANAGEMENT OF THEIR SYMPTOMS (Please select one)

Strongly comfortable	Uncomfortable	Not sure	comfortable	Very comfortable
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17) HOW WOULD YOU RATE YOUR LEVEL OF COMFORT WITH CARING FOR PATIENTS' SYMPTOMS (Please select one)

Very uncomfortable	Uncomfortable	Not sure	comfortable	Very comfortable
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PLEASE TELL US AS MUCH AS YOU CAN YOUR EXPERIENCES ON CARING FOR THE SYMPTOMS / CONDITIONS OF HOME BASED CARE PATIENTS

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**APPENDIX A (Setswana translation)**  
**DIPOTSOLOTSO**

**GO SEKASEKA KITSO,BOITSHWARO KA DIKAI,KALAFI LE THOMELO GO YA BONGAKENG MABAPI LE DIKAI TSE DI TLWAELESEGILENG GO AMANA LE MONGWE WA HIV/AIDS MO BOTSWANA.**

1. Matsalo ..... (Dingwaga )
2. Bong: Rre..... Mme.....
3. Seemo sa Lenyalo
  - a) Ga o a nyalwa .....
  - b) O nyetswe .....
  - c) O kgaogane le Monna kana Mosadi.....
  - d) Motlholagadi/Moswagadi .....
  - e) O a iphitlha .....
4. Tumelo
  - a)Muslim.....
  - b) Mokatoliki.....
  - c)Mokeresete.....
  - d)Tumelo tse dingwe.....
5. Seemo sa Thuto
  - a) Sekolo le le botlana.....
  - b) Sekolo se segolwane.....
  - c) Mmadikolo .....
  - d) Thuto ya Tlhaeletsanyo.....
6. Ke dife ditsela tse di farologanyeng tsa go amana le mogare wa HIV/AIDS?
7. Ke dife dikai tse di tlwaelesegileng tse o di boning mo balwetseng ba ba amilweng ke mogare wa HIV/AIDS?
8. O dira eng fa molwetse wag ago a nalelebebe mo molomong kgotsa dikodung?
9. O isa molwetse wa teng leng go bona ba bongaka?

10. Ke eng se se tswaelesegileng se tsala go huhula bosigo, go gotela, kgotholo ya lobaka lo lolele fa gongwe e tla le matlhasedi a madi mo molwetseng yo o amilweng ke mogare wa HIV/AIDS?

11. O dira eng ka molwetse wa teng?

12. O dira eng ka molwetse yo o nang le letlhatso la kgapetsa kgapetsa?

13. O mi isa leng bongakeng?

14. Molwetse yo o tshwanelwang ke go nna a rapame, o mo fetola go robala ka mohama o mongwe morago ga lebaka le le kae?

15. O itlhokomela jang gore o seka wa amiwa ke mogare wa molwetse yo o ka fa tlase ga tlhokomelo ya gago yo o nang le mogare wa HIV/AIDS?

16) O KA ITSHWAELA JANG MO TLHOKOMELONG YA GO HITSETSA MOLWETSE KO PELE MO GO ITLHOKOMELENG GA DIKAI TSA BOKOWA JWA BONE KA KGOLOLESEGO ( Tlhopho karabo e le nngwe )

Ke gololesegile mo go tlhomameng	Gake a gololesega	Gakena bosupi	Ke gololesegile	Ke gololesegile thata
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17) O KA ITSHWAELA JANG MO GO GOMOTSENG BALWETSE BA O BA TLHOKOMELANG BA NA LE DIKAI ( Tlhopho karabo ele nngwe)

Ke gololesegile mo go tlhomameng	Ga ke a gololesega	Gakena bosupi	Ke gololesegile	Ke gololesegile thata
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**INFORMATION SHEET (APPENDIX B)**

**TO DETERMINE HOME BASE CARE(HBC) VOLUNTEERS KNOWLEDGE ATTITUDE AND PERCEPTION OF DIAGNOSIS, TREATMENT AND REFERRAL OF COMMON SYMPTOMS ASSOCIATED WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) IN BOTSWANA**

My name is Dr.Patrick Akhiwu.

Thank you for the opportunity to meet with you and for taking time to read this.

As part of my requirement for my Masters degree in Palliative Medicine of the University of Cape Town, I have to conduct a research. I have chosen to carry out a study of Home Base Care(HBC) volunteers knowledge attitude and perception of diagnosis, treatment and referral of common symptoms associated with Acquired Immune Deficiency Syndrome (AIDS). I have chosen home based care volunteers in Botswana.

I would be grateful if you could take time to answer a few questions about the topic. Your participation will help in gaining a greater understanding of HBC's knowledge and management of AIDS symptoms in their daily activities of assisting patients with AIDS. Your assistance will be highly appreciated. However participation in this project is entirely voluntary and you are therefore free to consent to the interview or not. There will not be any penalty or reward for participation or not participating. Should you be willing to participate some questions will be asked of you and recorded . All your responses and answers will be confidential. There will be no link between your identity and your responses. Your right not to answer any question will be respected throughout the duration of the interview.

If you would like more information about this study do not hesitate to contact me on:

Telephone:- 6861411

6214252

71310099

Thank you

Dr. Patrick Akhiwu

**TSEBE YA THUTO (APPENDIX B – Setswana translation)**

GO SEKASEKA KITSO, BOITSHWARO JWA DIKAI ,KALAFI GA MMOGO LE THOMELO BONGAKENG MABAPI LE DIKAI TSE DI TLWAELESEGILENG DI AMANA LE MOGARE WA HIV/AIDS MO BOTSWANA

Leina la me ke Ngaka Patrick Akhiwu.

Ke lebogela sebaka sa go itsanye le wena, ga mmogo le nako e o e tsereng go bala se. Jaaka e le ntlha nngwe ya thutuntsho mo MASTERS IN PALLIATIVE MEDICINE mo Mmadikolo wa Cape Town, ke tshwanetse go dira patlisiso. Ke tlhophile go dira tshekatsheko ya Tlhokomelo ya Kwa Gae (HBC ) go sekaseka kitso, boitshwaro ka dikai, kalafi le malwetse a a tlwaelesegileng a amana le mogare wa HIV-AIDS. Ke tlhophile Tlhokomelo ya kwa Gae mo Botswana.

Ke ka leboga fa o ka tsaya sebaka sa go araba dipotso di se mmalwa ka Setlhogo se, Kopanelo tiro e, e ka thusa go fa tlhaloso ya konokono mo kitsong ya Tlhokomelo ya Kwa Gae le tlhokomelo ya dikai tsa AIDS mo botshelong jwa letsatsi le letsatsi go thusa balwetse ba ba amilweng ke mogare wa HIV-AIDS.

Thuso ya gago e ka lebosega fela thata. Le fa go ntse jalo, patlisiso e, e dirwa ka boitlhaopo, o gololesegile go araba dipotso kgotsa go tlhoka go di araba. Ga go ne go nna le katlholo ya go tlhoka go tsaya karolo mo patlisisong e. Fa o eletsa go tsaya karolo, itse fa dipotso dingwe di tla gatisiwa. Dikakgelo tsothe tsa gago le dikarabo di tla dirwa khupa marama. Ga go na go nna le go ntsha bosupi jwa mahatlha a gago ka go senola leina. O na le tshwanelo ya go se arabe dipotso, ebile tshwetso ya gago e tla amogelesega e tlotliwe go fitlhelela patlisiso e, e ya bokhutlong.

Fa o eletsa go nna le tshedimosetso go feta fa, o gololesega go itshwaraganya le nna mo megaleng e e latelang :-

- 6861411
- 6214252
- 71310099

Ke a leboga

Weno ruri,

**Patrick Akhiwu (Ngaka )**

**CONSENT FORM ( APPENDIX C)**

**TO DETERMINE HOME BASE CARE(HBC) VOLUNTEERS KNOWLEDGE ATTITUDE  
AND PERCEPTION OF DIAGNOSIS, TREATMENT AND REFERRAL OF COMMON  
SYMPTOMS ASSOCIATED WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME  
(AIDS) IN BOTSWANA**

I ..... declare that I have been informed and made to understand all that is in the information sheet (Appendix B )

2. I have been made aware that my participation in the above named project is completely voluntary and I am free to agree or not to agree to participate.

3. I am aware that there is no penalty or reward for participating or not participating

4. I am aware that I am free to withdraw at any time during this project.

5. Bearing in mind all the above I give my unreserved consent to participate in the above named project.

Name:.....

Signature :.....



**UNIVERSITY OF CAPE TOWN**



Research Ethics Committee  
E52 Room 24, Old Main Building Groot  
Schoor Hospital, Observatory, 7925  
Queries : Lamees Emjedi  
Tel : (021) 406-6338 Fax: 406-6411  
E-mail : lemjedi@curie.uct.ac.za

01 July 2005

**REC REF: 229/2005**

Dr L Gwyther  
Public Health & Family Medicine

Dear Dr Gwyther

**HOME BASED CARE (HBC) PROVIDERS KNOWLEDGE ATTITUDE AND PERCEPTION OF IDENTIFICATION TREATMENT AND REFERRALS OF COMMON SYMPTOMS OF ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) IN BOTSWANA**

*Thank you for submitting your study to the Research Ethics Committee for review.*

*It is a pleasure to inform you that the Ethics Committee has formally approved the above-mentioned study on the 24 June 2005.*

*However grave misgivings as to whether the scope of the study is adequate for a masters degree and would suggest that the supervisor work with the student to improve quality of questionnaire and extend of the study.*

*Please find attached attendance register of members attending meeting.  
Please quote the REC. REF in all your correspondence.*

Yours sincerely

**PROF T. ZABOW**  
**CHAIRPERSON**

