

UNIVERSITY OF NEW ENGLAND

THE EXPERIENCES OF NURSES PROVIDING COMMUNITY HOME-BASED
PALLIATIVE CARE TO PERSONS LIVING WITH HIV/AIDS IN BOTSWANA

A Dissertation submitted by

Tshepiso Daisy Chipisani-Mojapelo RN, BN, MScN

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Abstract

Prior to the HIV/AIDS epidemic that swept Africa in the 1980s, Botswana had one of the most effective healthcare systems in the developing world. Within a decade of the HIV/AIDS epidemic, Botswana's health system was overwhelmed, resulting in a reversal of the country's health indices. The epidemic significantly affected the way healthcare was delivered in the country. The rise in the number of people living with HIV/AIDS (PLWHAs), and the emergence of the host of non-communicable chronic diseases that accompany AIDS, has left hospitals in Botswana struggling to cope with the number of patients needing on-going care.

HIV/AIDS has had a huge effect on the management of people with chronic illnesses, and has led to the establishment of palliative and community palliative care programs in Botswana. As a result, patients have returned to their communities, where they receive community home-based care (CHBC) delivered by nurses, family members and volunteers. The current study was undertaken to better understand the CHBC nurses' views on the issues that affect them while delivering palliative care in the community to terminally-ill patients living with HIV/AIDS in Botswana.

The aim of the study was to explore the phenomenon of CHBC for PLWHAs in Botswana from the perspective of nurses delivering palliative care. The research question was: What is the lived experience of nurses delivering CHBC palliative care to PLWHAs in Botswana?

Interpretive hermeneutic phenomenology, a qualitative approach now widely used in health research was chosen as most appropriate for this study. van Manen's (1990) phenomenological approach was used to guide this study's investigative process because it was interpretive, open to innovation and emphasised dialogue

through self-reflection. van Manen (1990) outlines six broad guidelines for phenomenological study. These were followed in this study:

1. Turning to a phenomenon that interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it.
3. Reflecting on the essential themes that characterise the phenomenon.
4. Describing the phenomenon through writing and rewriting.
5. Maintaining a strongly-oriented pedagogical relationship to the phenomenon.
6. Balancing the research context by considering the parts of whole.

Ethical approval for the study was received from the James Cook University Human Research Ethics Committee and the Ministry of Health (MoH) Botswana. The researcher then wrote to the District Health Management (DHMT) coordinators of each participating district, explaining the purpose of the proposed study and requesting support in recruiting participants.

A purposive sample of 13 community nurses drawn from 12 districts of Botswana resulted in 13 interviews. Participants were initially asked the open-ended question: ‘What is it like for you to deliver community home-based palliative care to PLWHAs and with associated chronic illnesses in Botswana?’ All interviews were tape recorded with the consent of the participants, and transcribed verbatim.

Isolating thematic statements from the data involved asking what each sentence revealed about the phenomenon. The holistic approach sought to uncover the overall meaning of the text; the selective approach focused on outstanding

phrases and sentences of the text; and the line-by-line approach involved close examination of the text. What were called ‘themes’ were not necessarily the same thing said again and again, but rather an understanding of something significant that we wish to point the reader towards.

The study found that nurses are:

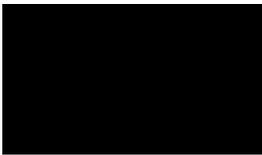
- *Working in chaos.* They struggle to deal with the consequences of governmental restructuring of the health system.
- *Struggling for advocacy.* They experience difficulties advocating for safe and effective patient care, including effective pain relief.
- *Dealing with HIV/AIDS stigma and discrimination.* They are challenged by the need to deal with the stigmatisation of the illness, both in the community and among HIV-positive nursing health professionals.
- *Committed to support volunteers.* They find it difficult to come to terms with the redistribution of responsibilities from nurses to volunteers.

The organisational change and restructure that occurred prior to the study had a significant effect on the way nurses deliver CHBC to PLWHAs. The role of CHBC nurses within the organisation was found to be minimal in terms of decision-making and advocacy. Home-based care nurses reported a sense of powerlessness in providing palliative care to PLWHAs and other patients cared for in the community. The nurses expressed frustration due to the lack of adequate support for the delivery of home-based care. The study identified that, although nurses valued the work done by volunteers, volunteers’ lack of training and support frustrated nurses. These issues, as well as nurses’ lack of theoretical knowledge of palliative care and a poor understanding of their advocacy role, inhibit nurses’ role as patient advocates. The

study concludes that there are inadequate human and material resources for the provision of quality home-based care.

Certification of Dissertation

I certify that the ideas, experimental work, results, analyses, software and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

A solid black rectangular box used to redact the candidate's signature.

Signature of Candidate

25/2/2017

Date

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List of Abbreviations

ABBREVIATION	NAME
AIDS	Acquired Immuno-Deficiency Syndrome
ARV	Antiretroviral Therapy
BAIS	Botswana AIDS Impact Survey
CHBC	Community Health Based Care
CSO	Central Statistics Office
DHAPC	Department of HIV/AIDS Prevention and Care
DHMT	District Health Management Teams
FWEs	Family Welfare Educators
HAART	Highly Active Antiretroviral Therapy
HCW	Health Care Workers
HIV	Human Immune Virus
MLG	Ministry of Local Government
MoH	Ministry of Health
NACA	National AIDS Coordinating Agency
NCD	Non-communicable chronic diseases
NGO	Non-Governmental Organisation
PCP	Pneumocystis carinii pneumonia
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary healthcare
PLWHAs	People Living With HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
PPE	Post Prophylactic Exposure
TB	Tuberculosis
UNAIDS	United Nations Programme on HIV/AIDS

UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly
UNICEF	United Nations Childrens' Fund
USAID	United States Agency for International Development
WHO	World Health Organisation

Chapter 1: Introduction

This study explores the experiences of community home-based care (CHBC) nurses in providing palliative care to people living with human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) (PLWHAs) in Botswana. Prior to the AIDS epidemic that swept Africa in the 1980s, Botswana had one of the most effective healthcare systems in the developing world. At that time, the national health system supported the increasing life expectancy (approximately 62 years) and declining rates of infant mortality (37.4 per 1000) (Botswana, Ministry of Health, Family Health Division, 1988). Unfortunately, within a decade, Botswana was overwhelmed by the global HIV/AIDS epidemic, resulting in a reversal of the health indices and a resurgence of tuberculosis (TB) (Botswana. Ministry of Finance and Development Planning. Central Statistics Office (CSO), 2001).

The HIV/AIDS crisis in Botswana swamped the healthcare sector (Dryden-Peterson et al., 2015). By 2001 Botswana had one of the highest rates of HIV/AIDS in the world; between 1996 and 2000, national prevalence rates as a percentage of the population aged 15-39 had reached 25.8% (World Bank, 2016). This significantly affected the way healthcare was delivered in the country (Ama, 2011; Thupayagale-Tshweneagae, 2007). Great strains were placed upon healthcare personnel, resulting in a significant shortfall in nurse, the largest component of the healthcare workforce (Botswana. Ministry of Finance and Development Planning, Central Statistics Office (CSO), 2006). Nurses are the professional group most likely to deliver healthcare in the community (Ladhani et al., 2014; Sinha & Onyatseng, 2013), so tend to experience high levels of stress due to heavy workloads, and often

have to deal with suffering patients with severely limited resources (Sinha & Onyatseng, 2013). The available evidence suggests that nurses in Botswana sometimes lack the knowledge and skills required to provide effective palliative care to home-based care patients (Fako et al., 2013). Nurses' lack of confidence and competency in palliative care can result in emotional stress, which can lead to job dissatisfaction (Sinha & Onyatseng, 2013). This has been observed and widely documented worldwide (Human Rights Watch, 2011; Rose & Glass, 2006; Silbermann & Al-Zadjali, 2013).

The rise in numbers of PLWHAs, the ever-extending periods of treatment with anti-retroviral (ARV) therapies (Eaton et al., 2014), and the emergence of a host of non-communicable chronic diseases that accompany AIDS, has left hospitals in Botswana struggling to cope with the number of patients needing on-going care. Consequently, patients have been returned to their communities as part of the continuum of care (Botswana Ministry of Health, 2010b; United States President's Emergency Plan for AIDS Relief (PEPFAR), 2013). The Botswana MoH (Botswana. Ministry of Health, 2010a) considers CHBC to be an integral part of the comprehensive model of palliative care (Mudanga et al., 2008). The continuum of care is a set of comprehensive and linked care, treatment and support services provided at all levels, from health facilities to community to home, defined as 'a continuum of prevention and care, where patients' needs are addressed by a network of providers over time' (Green & Horne, 2012, p.14).

ARV therapy at home requires close supervision of patients due to potential complications and other factors, such as drug uptake and adherence. Some cultural constraints in Botswana have made the delivery of AIDS services such as ARV

therapy, CHBC and palliative care more difficult. In their study on the constraints of ARV uptake in rural areas, Bene and Darkoh (2014) reported that some religious and cultural beliefs inhibited PLWHAs from taking ARVs. They reported that some community religious leaders even discouraged PLWHAs from attending clinics because they believed God would cure the disease. Further, they reported that mothers on prevention of mother-to-child transmission (PMTCT) programmes were either not taking their prescribed medications or continuing to breastfeed despite advice to the contrary. Refusal of treatment resulted in complications associated with HIV infections.

Initially, as the HIV/AIDS crisis accelerated, greater responsibility for the on-going care of PLWHAs in Botswana was handed over to community-based nurses. These nurses subsequently reported difficulties in managing the stress associated with providing community care to terminal patients and patients with chronic debilitating illnesses (Fako et al., 2013). However, little is known about their lived experience and the strategies they developed to manage the difficult work of caring for PLWHAs.

Evidence shows a reduction in numbers of HIV cases progressing to AIDS, and an improvement in patients' quality of life (Bongaarts et al., 2009). However, until now no Botswanan study has focused on describing the experiences of nurses who provide on-going care to patients. Results from the investigation into this topic will contribute to the knowledge on the provision of effective and efficient nursing care to palliative care patients in the community.

In Botswana, the majority of studies on palliative care have investigated organisational structures and systems with a focus on policy formulation and

available services (Botswana Ministry of Health, 2010a; Botswana National AIDS Coordinating Agency, 2010). A number of studies have focused on investigation of families and caregivers in Botswana. For example, Ama (2011) investigated the experiences and perceptions of PLWHAs under the CHBC programme in Botswana. His results showed that family members were key to providing care, and reported that they needed more support. Kang'ethe's (2010) results supported those conclusions, revealing that volunteers in Kanye found that volunteerism in home-based care challenged by poverty, heavy caseloads and the age of caregivers. Caregivers are predominately the elderly and frail. Kang'ethe (2010) concluded that more efficient and increased communication between hospitals, clinics and CHBC providers was desirable to improve home-based care.

1.1 Research Aim and Approach

The aim of this study was to explore the phenomenon of providing home-based care to PLWHAs in Botswana, from the perspective of nurses delivering palliative care. Interpretive hermeneutic phenomenology, an approach to qualitative research now widely used in health research, was chosen as the most appropriate for this study. Van Manen's (1990) phenomenological approach was used to guide this study's investigative process because it was interpretive, open to innovation and emphasised dialogue through self-reflection.

1.2 Rationale for the Thesis

The purpose of this research was to better understand the issues that affect nurses delivering palliative care to terminally-ill PLWHAs in the community in Botswana, as well as the nurses' views on these issues. The analysis of the nurses'

narratives about their experiences revealed patterns and trends that will inform the improvement of palliative CHBC for PLWHAs in Botswana, as well as improve nursing practice in the delivery of appropriate and effective care. If the issues that are important to nurses are understood, support systems can be improved for better care outcomes.

My experience around home-based care and dying patients in Botswana has informed my investigation of this subject. As a former CHBC nurse in Botswana, it was extremely confronting for me to see patients and families suffering, and nurses struggling to balance pain and other debilitating symptoms with the needs of patients and their families. My initial interest was in investigating nurses' experiences while delivering CHBC to PLWHAs in Botswana. However, my ideas and assumptions broadened as I read the literature and realised that, due to the introduction of ARVs, the lives of people with HIV/AIDS had been transformed from what was previously a death watch to a process of living with a chronic condition. As a chronic condition, HIV/AIDS is linked to on-going issues such as acquired co-infections and cancers, the management of which falls within the remit of already overworked CHBC nurses.

1.3 Locating the Researcher in the Context of This Study

My cousin was diagnosed with Kaposi's sarcoma. He helped me realise the pain and suffering that patients who have opportunistic infections from HIV go through without adequate pain management in Botswana. When I visited him in the village his condition had deteriorated, he was screaming in pain and my aunt, who was his caregiver, had little to offer. Being a nurse, I took him to the nearest clinic,

where the nurse on duty was helpless. My cousin's body was falling apart and was infested with maggots, so I arranged for his admission at a local primary hospital. However, as soon as I left the hospital he was sent back home as the nurses and doctors felt there was nothing they could do for him. After a long struggle, I managed to get him admitted to a referral hospital, with the hope that his pain would be adequately managed. However, even in hospital he had no order for an opioid analgesic. He suffered pain until his death.

As a senior nursing officer working for the AIDS Department, I shared the struggles with other nurses in providing and maintaining comfort for patients at home with limited resources. I have experienced the helplessness that comes with the absence of resources such as pain medication and transport. I shared my frustration with other home-based care nurses.

1.4 Situating the Research in Botswana

Botswana is a landlocked country with a population of two million people. It shares borders with South Africa to the south and southeast, Namibia to the west and Zimbabwe to the northeast. Geographically, Botswana is flat, with the Kalahari Desert comprising 70% of the country. Gaborone is the capital city, in the southern part of the country. Francistown, in the north, is the second largest city. Jwaneng is a mining town. Kgatleng, Ngwaketse, Kweneng and North East are major districts, while Serowe Palapye, Kweneng West and Mabutsane are sub-districts. Botswana is sub-divided into 26 health districts.



Figure 1. Map of Botswana. Area: 582,000 square kilometres.

(CIA, 2016)

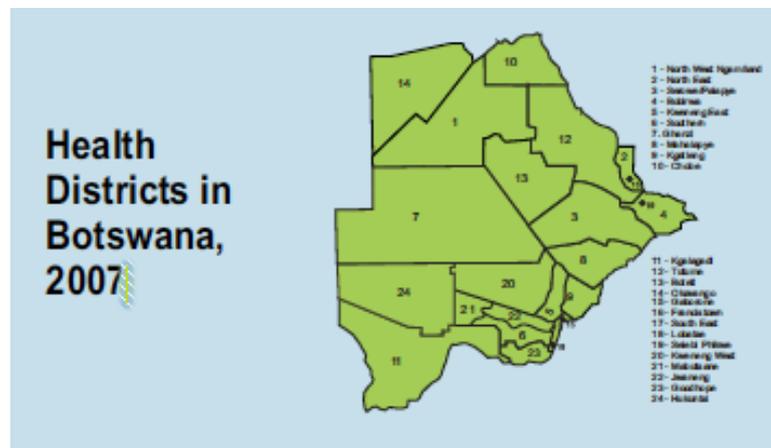


Figure 2. Map of Botswana health districts (Jimbo & Botswana. Department of HIV/AIDS Prevention and Care (DHAPC), 2005).

Recent estimates are that 22% of households in Botswana live below the poverty line. In urban areas it is 11.7%, while in rural areas it is at 27.1% (Bene &

Darkoh, 2012). Some CHBC patients live in abject poverty and have few resources (Ama, 2011). In such households, often no-one has employment or an income adequate to maintain the family (Rajaraman et al., 2006). Families are usually large, with low levels of education and limited job opportunities (Statistics Botswana, 2013). Those with no resources mainly depend on the government's food basket programme (Seleka et al., 2007), or its modern replacement, the coupon (smartcard) that allows beneficiaries to acquire the specified foodstuffs at participating shops (World Bank & Botswana Institute for Development Policy Analysis, 2013, p. 24).

SSN programme	Eligibility criteria	Packages
(1) The Destitute Persons Programme	<ul style="list-style-type: none"> Individuals unable to engage in sustainable economic activities, due to disability or chronic health problems. Individuals with insufficient assets or income sources; should have less than 4 livestock units, and should earn income less than P120/month without dependents or P150/month with dependents. Individuals who due to physical or mental disability are incapable of engaging in sustained economic activity, as determined by a health practitioner. Individuals who due to emotional or psychological disability are incapable of engaging in sustained economic activity, as determined by a social worker. Children under 18 living under difficult circumstances. Individuals who are terminally ill. 	<ul style="list-style-type: none"> According to the policy, permanent rural destitute persons receive food packages amounting to P211.90 per month. Their urban counterparts receive food packages worth P211.40 per month. However, the figures may go up, depending on the cost of the approved food basket. According to the policy, temporary destitute persons receive monthly food rations valued at P181.90 in rural areas, and P181.40 in urban centres. However, the figures may go up, depending on the cost of the approved ration. Both permanent and temporary destitute persons receive an additional P70.00/month (in cash) for personal (non-food) items. Provisions are made for shelter (if needed), medical care, occasional fares, funeral expenses, and exemptions from service levies, taxes, water charges, street licenses and school fees, and tools required for rehabilitation.
4) Community Home Based Care Programme	<ul style="list-style-type: none"> Provides optimal care for terminally ill patients in their local environment. While it was established in response to the HIV/AIDS epidemic, it covers those patients with other conditions as well. The basket is provided to needy patients only. Assessment guidelines for the destitute programme are applied. 	<ul style="list-style-type: none"> Provides food baskets based on recommendations by a doctor or dietician; thus no price is attached to the food basket. In practice, the cost of food baskets has ranged from P200 to P1,500 per patient per month.

Figure 2. Food basket programme

(Seleka et al., 2007)

The government has a social welfare programme that provides monthly food for needy patients after their discharge from hospital (Botswana Ministry of Health. AIDS/STD Unit, 1996; Botswana Ministry of Local Government, 2011). Patients should be referred to the programme through their health facility after being assessed by a doctor, and must be assessed for eligibility by social workers (Botswana Federation of Trade Unions, 2007, p. 28), then be prescribed by a government dietician (United Nations Development Programme & International Poverty Centre, 2005, p. 134).



Figure 3. Typical dwelling in Botswana for people with limited resources (TshepisoDaisy Chipisani-Mojapelo, 2012).

1.5 Background to Global HIV/AIDS

According to the World Health Organization (WHO) (World Health Organization, 2015a), HIV continues to be a major global public health issue, having claimed more than 34 million lives so far. At the end of 2015, an estimated 36.7 (34.0-39.8) million people were living with HIV worldwide (UNAIDS, 2016; World Health Organization, 2015a). As of June, 2016, 16.1-19.0 million PLWHAs were accessing ARV therapy, from 15.8million in 2015 and 7.5 million in 2010 (UNAIDS, 2016). UNAIDS is aiming to end the epidemic by 2030 (UNAIDS & Joint United Nations Programme on HIV/AIDS, 2014), thus averting 18 million new infections and 11.2 million AIDS-related deaths between 2013 and 2030 (UNAIDS & Joint United Nations Programme on HIV/AIDS, 2014; World Health Organization, 2015a). As of June 2015, 15.8 million PLWHAs were receiving ARV therapy (UNAIDS, 2016), including 823,000 children (41% of those in need) (AIDS.gov, 2015). By mid-2015, 54% of infected people knew their status (World Health Organization, 2015a).

Expanded access to ARV therapy and a declining incidence of HIV infection have led to a steep drop in the number of adults and children dying from HIV-related causes, globally. The estimated 1.5 million (1.4–1.7 million) people who died from HIV globally in 2013 represented a 22% decrease from 2009, and a 35% decrease from 2005, the peak. In 2013, 31% fewer children (under 15 years) died from HIV compared to 2009, and 40% fewer than in 2005 (World Health Organization, 2016). As the global HIV/AIDS pandemic enters its third decade, the number of new infections in Sub-Saharan Africa has fallen by 25% (UNAIDS, 2010). Sub-Saharan Africa remains the most affected region 25.8 (24.0–28.7) (World Health

Organization, 2015a), accounting for 70% of total global HIV infections (AIDS.gov, 2015; World Health Organization, 2015a). According to UNAIDS (UNAIDS, 2015), the number of AIDS-related deaths in Sub-Saharan fell by 48% between 2004 and 2014, while 790,000 people died of AIDS-related cause (UNAIDS, 2015). Of these, 2.6 million were children, most of whom were infected by their mothers during pregnancy, childbirth or breastfeeding (AIDS.gov, 2015).

According to UNAIDS (UNAIDS & Joint United Nations Programme on HIV/AIDS, 2014), nearly 90% of people who know their HIV-positive status are now on ARVs, with 76% having a low viral load. However, most PLWHAs in resource-constrained settings do not have access to care or treatment (World Health Organization, 2015a).

An important consequence of the HIV/AIDS epidemic in Sub-Saharan Africa is that, as of 2012, an estimated 15,100,000 children (aged 0–17) had lost one or both parents due to AIDS (United Nations Children’s Fund (UNICEF), 2013, p. 81). It is estimated that 17.8 million children below the age of 18 have been orphaned by AIDS, which was predicted to rise to 25 million by 2015 (AVERT, 2015a, p. 1). In most Sub-Saharan countries, 20% or fewer orphaned children receive some form of support. According to UNICEF (United Nations Children’s Fund (UNICEF), 2015), in the countries most affected by HIV (e.g., Swaziland, Lesotho and Botswana), more than 1 in 10 females between 15 and 24 are living with HIV, and appear to have been infected by an older man.

Poor people are still the major victims of HIV/AIDS (Shah, 2009). Many of the African countries hardest hit by HIV also suffer from other infectious diseases, food insecurity, poverty and diminished opportunities to access ARVs, all of which

compound the HIV/AIDS problem (Africa Check, 2014). While poverty is undoubtedly a major contributor to the severe effect of HIV/AIDS in Africa, governments must exhibit the political will to limit the effects of HIV/AIDS (Shah, 2009). The HIV/AIDS epidemic means that more healthcare must be delivered in the community, because at present the burden is felt most strongly by nurses, volunteers and their communities.

1.6 HIV/AIDS in Botswana

Botswana has been identified as the country with the highest rates of HIV infection in the world (Jensen et al., 2012). Infection is estimated to be around 17.6% for the general population and 24% for the 15 and above age group; 48.9% of women aged 30–34 years are infected and 33.3% of pregnant women are HIV-positive (UNDP in Botswana, 2012). Botswana NACA (Botswana. National AIDS Coordinating Agency, 2015) estimated that Botswana had 390,000 (370,000–410,000) PLWHAs in 2014. The fourth Botswana AIDS Impact Survey BAIS IV (Statistics Botswana, [2014]), estimated HIV prevalence to be 18.5% for the general population aged 18 weeks and over, with female prevalence at 19.2% and male at 14.1%, a slight increase from BAIS III (Botswana Ministry of Finance and Development Planning. Central Statistics Office (CSO), 2009). BAIS III estimated rates at 17.6%, 20.4% and 14.2%, respectively (Botswana National AIDS Coordinating Agency, 2015. p. 15). HIV prevalence data varied slightly depending upon residence and district, with urban estimates at 19.2% and rural at 17.4% (Statistics Botswana, 2014, p. 10).

The extreme mobility of populations and the significant urbanisation of Botswana has contributed to the rapid spread of HIV/AIDS, leading to the

breakdown of traditional mechanisms for controlling social and sexual behaviours (Botswana Red Cross Society, 2006; Botswana National AIDS Coordinating Agency, 2010). Other factors believed to have facilitated the spread of HIV in Botswana include:

- Multiple sexual relationships and inconsistent use of protective measures such as condoms;
- High rates of other sexually transmitted infections;
- Improved road networks, which have facilitated easy movement between regions (Botswana. National AIDS Coordinating Agency, 2010, p. 2).

The last two BAIS reports also show that HIV transmission is still exacerbated by declining use of condoms, from 90.2% (BAIS III), (Botswana Ministry of Finance and Development Planning. Central Statistics Office (CSO), 2009) to 81.9% (BAIS IV) (Statistics Botswana, [2014]) by women and men aged 15–49 years who had more than one partner in the 12 months before the survey (Botswana. National AIDS Coordinating Agency, 2015, p. 6). In BAIS IV, first-time sexual intercourse below the age of 15 was reported in 4.4% of men and women aged 15–24, compared to 4% in BAIS III. Further, 15.8% of women and men aged 15–49 had sexual intercourse with more than one partner in the previous 12 months (Statistics Botswana, [2014]), p. 15). Botswana NACA (2015, p. 6) has stated that Botswana must invest more in behavioural interventions specifically aimed at reducing multiple concurrent sexual partnerships.

HIV/AIDS has affected the health sector's ability to cope with the provision of medical care in Botswana, as nearly half of hospital admissions are due to HIV

infection and associated opportunistic infections (Botswana National AIDS Coordinating Agency, 2010; Statistics Botswana, [2014]).

Stigma and discrimination are major constraints to universal access to, and utilisation of, HIV/AIDS services. A diagnosis of HIV/AIDS comes with high stigma in Botswana, especially in mother-to-child situations (Gourlay et al., 2013). Stigma has been recognised as a human rights issue in Botswana. The National Framework on HIV and AIDS recognises the need to address all forms of stigma and discrimination that ‘collude to constrain the coverage and effectiveness of HIV and AIDS interventions and increase the vulnerabilities of particular groups in society’ (Botswana Department of HIV/AIDS Prevention and Care (DHAPC), 2012; UNDP in Botswana, 2012). Stigma may affect many aspects of the lives of PLWHAs, such as through healthcare, employment, community and household discrimination, and restrictions on entry, travel and stay (AVERT, 2015c). According to the Global AIDS Progress Report in Botswana (Botswana. National AIDS Coordinating Agency, 2015 p. 25), 13.2% of women and men aged 15–49 reported that they experienced some discriminatory attitudes. However, the Botswana Stigma Index Survey 2013 indicated that most PLWHAs experienced internalised stigma (24%) compared to external stigma (13%) (Botswana National AIDS Coordinating Agency, 2015, p. 25). Weiser et al. observed in Botswana some unwillingness to care for infected family members, and Kang’ethe (2009) reported that PLWHAs might reject the services of health professionals from fear of being identified as HIV-positive (Kang’ethe, 2009; Weiser et al., 2006). Additionally, it was found that family members may conceal the status of the patient or be reluctant to accept care from health professionals because of fear of the associated stigma.

In Botswana, as in any country with a high prevalence of HIV/AIDS, an increasing number of PLWHAs are receiving ARV therapy (Dryden-Peterson et al., 2015; Farahani et al., 2016). The most notable outcome of ARV programmes was that from 2002–2010, when 100,000 adult patients were enrolled in the programme, mortality rates decreased from 12.6% to 1.16% after treatment (Farahani et al., 2016). According to NACA (2015), as of December 2014, there were 247,947 adults and children receiving ARV therapy in Botswana, 63.2% of total people living with HIV (lower than the 69.9% recorded in 2013) (Botswana National AIDS Coordinating Agency, 2015). A total of 8578 of these were children (Botswana National AIDS Coordinating Agency, 2015, p. 22). Although the ARV programme has done well since its inception, there are concerns over declining follow-up rates among adults. There are also high treatment failure rates among adults, an increase from less than 6% in 2012 to over 10% in 2013 (Botswana National AIDS Coordinating Agency, 2015, p. 6). Additionally, NACA (2015) observed that ARV therapy coverage is compromised by the low testing rates (63.7% of the population aged 15–49 years) (Botswana National AIDS Coordinating Agency, 2015, p. 7).

The government's decision to provide free ARV therapy to its citizens has contributed to large numbers of Botswana accessing ARV therapy and living longer with the illness and its related conditions (AVERT, 2015b). It was estimated that in 2013, around 213,953 adults with HIV were receiving ARV treatment, reflecting 69% coverage (AVERT, 2015b, p. 1). Coverage for children has also increased, to 84% (Farahani, quoted in (AVERT, 2015b, p. 1).

While mortality rates have fallen in countries where ARV drugs are available, chronic conditions resulting from or related to HIV are on the increase

(Quinn, 2008). ARV therapy reduces the viral load, thus delaying the progression to AIDS and reducing morbidity and mortality (Wasti et al., 2012). Rigorous adherence to ARV therapy is necessary to suppress viral replication, improve immunological and clinical outcomes, and decrease the risk of developing ARV drug resistance (World Health Organization, 2012).

Unfortunately, in Botswana, despite the extended effort to promote high levels of treatment adherence, substantial rates of non-adherence have been reported (Ehlers & Tshisuyi, 2015; Ndiaye, 2014; Ndiaye et al., 2013). Despite the success of ARV interventions, their cost has significantly affected the government budget. Thus, increasing the delivery of chronic and palliative care in Botswana may be unsustainable. As Lule and Haacker have stated: ‘The increased burden of HIV-AIDS...has therefore been met from two sources, the benign economic environment...and the increase in external support...it is not clear whether either of these sources will continue to meet the fiscal burden of HIV/AIDS’ (Lule & Haacker, 2011, p. 76). Hospitals often cannot cope with high numbers of chronically ill patients, so discharge patients early (Mudanga et al., 2008).

1.7 Comorbid Chronic Conditions

The world’s response to HIV/AIDS over the past three decades has gone through several transformations, including the development and widespread distribution of ARVs (Deeks et al., 2013; Joint United Nations Programme on HIV/AIDS (UNAIDS), 2012; Nguyen, 2009; Padian et al., 2011). PLWHAs face many challenges in their everyday lives: they report lower quality of life attributed to their physical and psychological symptoms, such as pain, fatigue and complicated medication regimes (Braithwaite et al., 2008; Lowther et al., 2012). ARV therapy,

while helpful, does not restore PLWHAs' immune systems. Most PLWHAs are immune-compromised and remain susceptible to AIDS-related complications (Deeks et al., 2013). Cancers, such as Kaposi's sarcoma and invasive cervical cancer, are common among PLWHAs (Fausto & Selwyn, 2011), along with cardiovascular disease and diabetes (Deeks et al., 2013; van Olmen et al., 2012). Lazenby et al. found that out of 100 cancer patients, 48 were HIV-positive and 23 had gynaecological malignancies (Lazenby et al., 2015). Given the growing number of PLWHAs requiring long-term care and support, it is becoming increasingly important to develop long-term care modalities (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2012; Lynch et al., 2012).

In developing countries, ARV therapy has effectively prolonged the lives of many PLWHAs, so the current focus of government policies is advocacy and the institution of appropriate systems (Haregu et al., 2013; Haregu et al., 2014; van Olmen et al., 2012). When the disease first appeared, due to its fatal progression in the absence of intervention, HIV/AIDS was considered to be different from other chronic conditions (Haregu et al., 2014). Since the advent of ARV therapy, the management of AIDS has been subsumed in chronic disease management (Haregu et al., 2014; Joint United Nations Programme on HIV/AIDS (UNAIDS), 2012; United Nations General Assembly, 2011) UNGASS.

The UNGASS has acknowledged the importance of linking HIV/AIDS and non-communicable chronic diseases (NCD) (Haregu et al., 2013), as they have common risk factors that affect disease progression in PLWHAs (Haregu et al., 2014). There has been a growing focus on chronic diseases in Sub-Saharan Africa (van Olmen et al., 2012). As a result of the illness and chronic disease experienced in

this region, there is a need to provide a strong primary healthcare model that includes palliative care (Bodilenyane & Motshegwa, 2012b).

In most low and middle-income countries, chronically ill patients consume more services for both acute and home-care services (Abegunde et al., 2007). In Africa, mortality rates due to chronic disease, including HIV/AIDS, are higher (69% of deaths) than anywhere else in the world (Aikins et al., 2010). For example, the number of patients with hypertension, diabetes and cancer is increasing (Abegunde et al., 2007; Aikins et al., 2010; Bodilenyane & Motshegwa, 2012a). The WHO envisaged the need to reduce the burden of chronic disease by 2% every year between 2005 and 2015, to prevent 36 million deaths by 2015 (Aikins et al., 2010). As living with a HIV/AIDS and chronic illness poses various challenges to nurses, being well-versed in the complexities of managing chronic illnesses is necessary.

In Botswana, PLWHAs commonly experience associated chronic illnesses, such as TB, diarrhoea, meningitis, pneumocystis carinii pneumonia (PCP) and malaria, thus overburdening the health system (Bodilenyane & Motshegwa, 2012a). The health sector must prioritise the link between HIV/AIDS and chronic conditions in order to increase and improve the delivery of services at all levels. The need to strengthen primary healthcare (PHC) services must not be underestimated, as they are often the only services accessible to vulnerable communities.

1.8 Healthcare Services in Botswana

Health is a priority for the Government of Botswana, especially the provision of equitable health in both urban and rural areas (Sinha & Onyatseng, 2013).

Although donor support exists in Botswana, the government largely funds its own health services (World Health Organization, 2014). HIV/AIDS, malaria and TB (and

TB multi-resistant drug strain) have been challenges to healthcare, with 69% of adults on ARV therapy (AVERT, 2015b). Services remain free for the all vulnerable groups in Botswana, as outlined in the National Health Policy (Botswana Ministry of Health, 2011). An essential health package was defined in 2010 (Botswana. Ministry of Health, 2010a), based on ‘cost effective interventions, which covers 80% of the care to be delivered, ensuring equal access for both rural and urban populations’ (World Health Organization, 2015b). According to Sinha and Onyatseng (2013, p. 111), 84% of the population of Botswana live within a five-kilometre radius, and about 95% within an eight-kilometre radius, of health facilities, yet patients without transport are still disadvantaged. Although efforts are being made to strengthen the healthcare system, social determinants of health such as poverty, low levels of education and the rise in HIV/AIDS cases have had a huge effect on the success of the system. To ensure the future success of its health strategy and repair the damage HIV/AIDS has caused to its economy, Botswana has been advised that:

the provision of basic services focused on human capacity development would help to offset the negative poverty impact, specifically policies focused on basic health and nutrition; HIV-related counselling support for the youth; and improving the effectiveness of the anti-AIDS campaign (Jefferis et al., 2006, p. 115).

1.9 Structure of the Health System

Botswana’s PHC service comprises 101 clinics with beds, 171 clinics without beds, 338 health posts and 844 mobile stops (Botswana Ministry of Finance and Development Planning, 2011). Despite these resources, the health sector still faces

challenges in increasing access to health services for vulnerable groups, such as remote-area dwellers. Health services in Botswana are delivered through public, private for profit and non-profit organisations. The MoH is responsible for the formulation of policies, standards and guidelines (Botswana Ministry of Health, 2011). Primary care is provided through primary health centres, district and referral hospitals, and private and mission hospitals. PHC services are provided through a network of clinics, health posts and mobile stops, as well CHBC programmes.

In Botswana, the shortage of human resources for health remains one of the major blocks to health improvement, as it cuts across all health issues and has a huge effect on service delivery. Despite the government's efforts to retain health workers, poor working conditions, low wages and the demands of HIV/AIDS care have led to staff attrition (Seitio-Kgokgwe, 2012). One of the aims of Vision 2016 is that all Botswana should have access quality healthcare services (Botswana National Vision Council, 2010). To achieve this, the government aimed to create a skilled and motivated health sector workforce (Botswana Ministry of Health, 2011, p. 1).

1.10 Traditional Healers

Until the 1970s, traditional healers provided the only healthcare services to most Botswana. With the rise of Western medical services, traditional healers' influence has declined, but only in the more formally educated segment of Botswanan society. As the WHO has acknowledged, 'Traditional healers are well respected and influential in rural areas and remain central figures in the everyday lives of the majority of the rural population' (World Health Organization, 2001, p. 6).

The National Health Policy (Botswana. Ministry of Health, 2011) stipulates that the government shall provide the regulatory framework for alternative medicine practice and create an enabling environment for effective involvement of traditional practitioners, as well as the efficacy of traditional medicinal plants. Although traditional medicine is widely used in Botswana, there is no framework to regulate its practice (Botswana Ministry of Health, 2011). The MoH has no formal structure for collaborating with traditional and faith healers, something that is needed in the future, as these healers still play an important role in the lives of many Batswana.

1.11 Restructuring of Botswana's Health Sector

A number of government reforms have been undertaken in the last decade, including the decentralisation of health services (Botswana Ministry of Health, 2011). In 2000, the Botswana healthcare system underwent a review, which resulted in a significant organisational restructuring in the area of public health administration (Botswana Ministry of Health, 2010b; Seitio-Kgokgwe, 2012). In her study assessing the impact of organisational structure, Seitio-Kgokgwe concluded that the structure fitted well with government policy objectives. However, there were challenges with its implementation, attributed to a failure in management processes, a lack of staff to undertake new roles and power being over-centralised at the MoH (Seitio-Kgokgwe et al., 2014).

In 2009, when it became apparent that there was poor coordination between the MoH and Ministry of Local Government, the WHO provided both financial and technical support to the MoH restructuring process, in order to address the changing health environment and improve the performance of the new structure (World Health Organization, 2015b). According to the Minister for Health, Ms Dorcas Makgato, the

main aim of restructuring was to harmonise and align functions of both the MoH and District Health Management Teams, in order to improve the efficiency and effectiveness of service delivery by ‘empowering District management, conducting organisational restructuring that advocates for decentralisation (lean headquarters and autonomous district management teams) and separating policy development and regulatory functions from service delivery functions’ (Thatayamodimo, 2015, p.1). One of the objectives of this restructuring was to allow the MoH to distribute functions to District Health Management Teams (DHMTs), and to ensure that they received the required support from all central departments (Botswana. Ministry of Health, 2011).

The healthcare system in Botswana had traditionally followed a decentralised model, with PHC being managed and coordinated by the Ministry of Local Government and DHMTs (Botswana Ministry of Health, 2010b). In April 2010, the Primary Health Care Coordinating Committee and District Primary Health Coordinating Committees were handed responsibility for ensuring harmony and a good working relationship between MoH and Ministry of Local Government (MLG) (Botswana Ministry of Health, 2011). The aim of the exercise was to facilitate the decentralisation of responsibilities to the districts for better service delivery. In reality, this has increased the bureaucratic role of the MoH and reduced the autonomy of the districts. According to a report by HURAPRIM, the relocation has made DHTs subservient to hospitals, and this has compromised community services (Human Resources for Primary Health Care in Africa (HURAPRIM), 2010).

Under the previous structure, the MLG was responsible for the oversight and delivery of health services in Botswana, while the MoH was responsible for the

formulation of policies, regulation and norms, standards and guidelines for the country's health services. The MoH was a major provider of health services through a wide range of facilities and management structures (Botswana Ministry of Health, 2011). The MLG was previously charged with providing PHC through a network of clinics, health posts and mobile stops, as well as community-based preventative and promotional services. In 2010 these services were relocated to the MoH (Botswana Ministry of Health, 2011, p. 7). The decentralisation of health services in Botswana had previously had a positive impact on the implementation of grassroots services. Dispersal of health service responsibilities to local authorities had been ideal for the districts, through establishing strong local accountability.

The previous structure was built on the basis of units, which were organised to deal with single diseases. The emphasis was on vertical disease programmes, resulting in constraints that overburdened the healthcare system. Under the new structure the vertical programmes were allocated to departments. This resulted in the MoH having six departments, comprising the Department of Policy Planning and Evaluation, the Department of Health Sector Relations and Partnership, the Department of Clinical Services, the Department of Public Health, the DHAPC and the Department of Ministry Management. The DHAPC manage programmes implemented at district level, and deal directly with the districts. There was a noticeable increase in new positions at the MoH, to align with the new departments. The establishment of new roles at the district level was one of the critical issues during the restructure, and the relationship between the national level and the implementing level was hardly addressed at all. According to the Human Resource for Primary Health Care (Human Resources for Primary Health Care in Africa

(HURAPRIM), 2010), inadequate support and supervision by the MoH was a significant cause of nurses' dissatisfaction with the restructure. The DHMT lacked guidance in the implementation of the new structure.

Some effects of the policy changes including lack of key resources such as transport, technical support and supervision have made nurse visits to the districts a challenge (Ama, 2011). The general opinion at the district level is that the MoH does not see the districts' role in contributing towards the change, which results in lack of their involvement and ownership as implementers. The districts often complained about the lack of autonomy and extensive interference by the MoH (Human Resources for Primary Health Care in Africa (HURAPRIM), 2010). This illustrates the need to repair the relationship between the MoH and the districts for better service delivery.

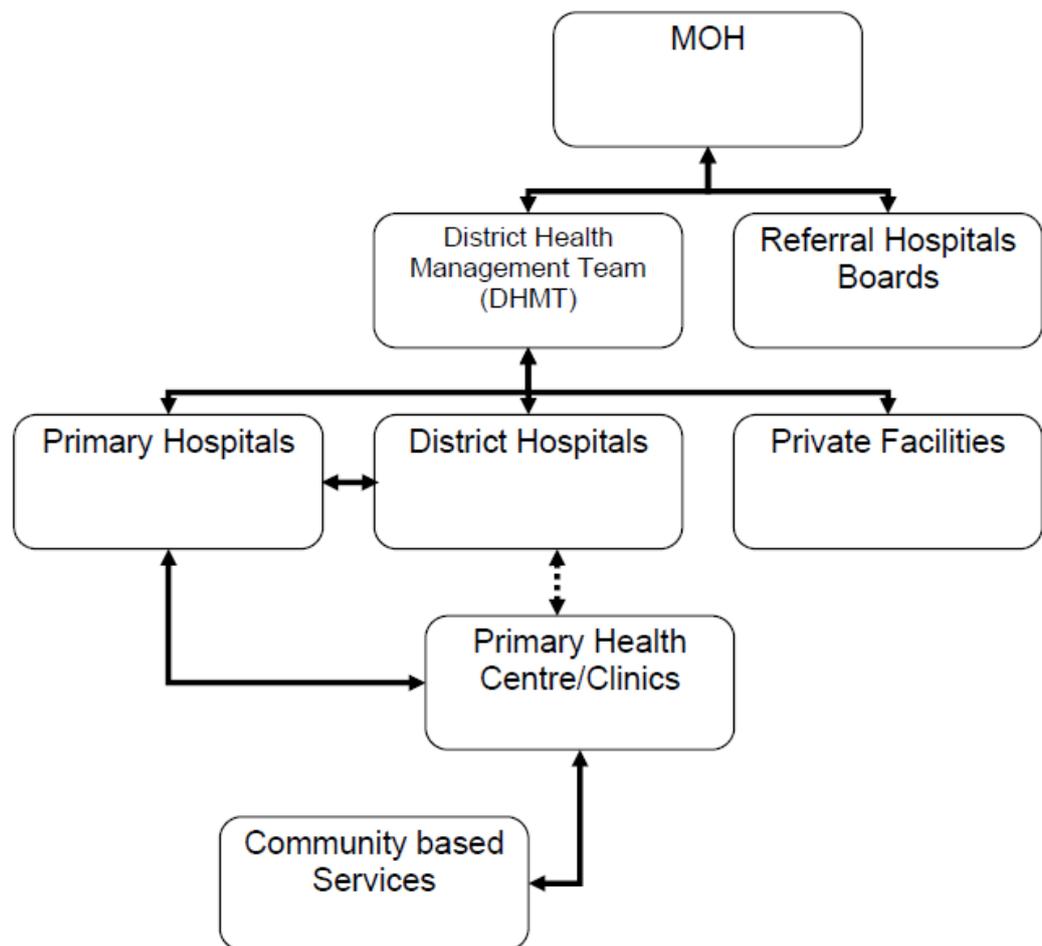


Figure 4. The Botswana healthcare system underwent a review (Botswana Ministry of Health, 2011, p. 38).

1.12 The Development of Palliative Care in Botswana

The national response is also being prepared for increase in non-communicable diseases resulting from AIDS treatment regimens, and the high treatment failure rates for adults due to poor adherence (Botswana National AIDS Coordinating Agency, 2015). In a press release, Makgatho indicated that the Government of Botswana was concerned about the increase of non-communicable diseases such as cardiovascular disease, cancer, diabetes and chronic lung diseases

(Thatayamodimo, 2015). These, as well as infectious diseases such as HIV, prompted the initiation of community-based palliative services (Ama, 2011; Ama & Seloilwe, 2011; Bodilenyane & Motshegwa, 2012b). In 1995, Botswana introduced the CHBC programme to provide care and services to patients living with HIV/AIDS and other terminal illnesses (Botswana Ministry of Health. AIDS/STD Unit, 1996; Mudanga et al., 2008).

Although PLWHAs can be healthy, strong and live a normal life, they can also experience a range of symptoms for which they will continue to need support. The need for efficiency and equity in the delivery of healthcare has resulted in the wide use of CHBC in Sub-Saharan Africa, and this allows PLWAs to be cared for at home, long-term (Jang & Lazenby, 2013). Studies have shown that the potential benefit of home-based palliative care is that sick people remain in a familiar environment. During the inevitably stressful process of caring for a family member with a terminal or chronic illness, families need additional support because they are vulnerable (Shanmugasundaram & O'Connor, 2009; Sinha & Onyatseng, 2013). Community palliative care in Botswana aims to promote the physical and psychological wellbeing of patients whose disease is no longer responding to curative treatment. The aim is to integrate the psychological and spiritual aspects of care, and to support patients and families in the provision of comfort and promotion of death with minimum pain and maximum dignity (Kang'ethe, 2009; Mudanga et al., 2008).

Botswana has adapted the WHO definition of palliative care, which is that it is:

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 of and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization, 2015c).

Palliative care has been described by Family Health International as an essential part of the continuum of care for patients cared for at home (Family Health International, 2008, p.11). The Botswana Palliative Care Programme was built on the available home-based care model, to meet the holistic needs of patients. There was consultation between and among stakeholders at all stages; that is, the MoH, local government, districts and civil society organisations.

Following consultations in 2003, the Botswana MoH (Botswana. Ministry of Health, 2010b) conducted a situational analysis on patients' and caregivers' needs (Mudanga et al., 2008). The study results revealed an increased demand for palliative care due to the high number of PLWHAs with their resulting chronic conditions being cared for at home. Additionally, the findings highlighted that, due to limited palliative care services, the needs of terminally-ill patients and their families were not being met. The report also revealed that pain and other symptoms of the terminally ill were not being adequately managed (Botswana Department of HIV/AIDS Prevention and Care (DHAPC), 2012; Mudanga et al., 2008). The factors contributing to poor pain and symptom management included lack of understanding of palliative care by healthcare professionals, lack of palliative care protocols and

restrictive laws on accessing opioids and other strong analgesics in Botswana (Botswana. Department of HIV/AIDS Prevention and Care (DHAPC), 2012; United States President's Emergency Plan for AIDS Relief (PEPFAR), 2013).

Despite intentions to make palliative care available at the community level, because of the lack of trained health workers it was not possible to offer comprehensive care in the community. The chronic shortage of nurses and doctors with only four physicians and 27 nurses servicing 10,000 people has been another other contributing factor to the difficulties of offering palliative care in the community (United Nations Development Programme, 2013). Despite the fact that nurses are the largest group of professionals in healthcare in Botswana, there are an inadequate number of nurses to service the widely-distributed population (African Health Observatory & World Health Organization. Regional Office. Africa, [2014]; Botswana Ministry of Health, 2009). Nursing shortages and high workloads are a recurring problem in Botswana, and provide a major impediment to implementing effective palliative care.

1.13 Outline of Thesis

Chapter One has provided a justification for the study, followed by the research aim, questions and an overview of phenomenology. The context of the study was also described and discussed. This discussion included a global view of HIV/AIDS and a more focused examination of this disease, specifically as it affects Botswana and the Botswana healthcare system. Chapter Two reviews the literature relevant to the topic. Methodology and methods chosen for the study are explored in Chapter Three. Chapter Four reports the study findings, and Chapter Five places these findings in the context of the contemporary literature. The final chapter

summarises the outcomes of the study, evaluates the quality of the study processes and products, and makes recommendations for practice, education and research.

1.14 Conclusion

This chapter has addressed the genesis of this research and its foundational development. It detailed my professional commitment to home-based care and previous involvement in nursing practice in Botswana. In the background information, I provided the research context and situated the research in Botswana. The global HIV/AIDS situation and that of Botswana has also been discussed, as has the transit of HIV/AIDS from a life-ending to a chronic condition. I introduced the structure of the Botswana health system. The chapter concluded with an outline of the development of palliative care in Botswana. Based on these foundations, the following chapter presents a review of the literature relevant to the research question.

Chapter 2: Literature Review

2.1 Introduction

This chapter places the research in context by reviewing the literature related to the research question: What is the lived experience of CHBC nurses delivering community home-based palliative care to PLWHAs in Botswana? This chapter is divided into three sections: the management of HIV/AIDS patients and related chronic conditions through palliative care; the role of community-based nurses in providing palliative care; and the experiences of nurses working with families in community-based care.

As palliative care encompasses many disciplines such as nursing, medicine, social work and religion there is an abundance of palliative care literature. Tieman, Abernethy, Fazekas and Currow argue that because there is so much documentation, the task of evaluating this literature requires a systematic approach, with clear search boundaries and definitions (Tieman et al., 2005, p. 2236). This opinion is echoed in Harding et al.'s comprehensive review of the current status of palliative care in Sub-Saharan Africa, which describes a wealth of anecdotal clinical academic experience (Harding et al., 2013a). However, Harding et al. (2013) have claimed that there is currently a dearth of methodologically robust evidence. Therefore, I surveyed the literature with an open mind and reviewed it critically. Rather than providing an exhaustive account of palliative care literature as a whole, attention was focused on issues pertaining to CHB palliative care for PLWHAs and resulting chronic conditions. Consequently, I found there to be a dearth of literature on palliative care for PLWHAs in home-based care. It is this knowledge gap that the current research attempts to address.

Palliative care aims to meet the needs of patients by relieving their symptoms, and nurses play an integral role in its promotion and provision (Fitch et al., 2015). However, it is not easy process for nurses in many parts of the world (Fitch et al., 2015). My intention was to document nurses' interpretations of the role of caring for such patients at home, in a developing country.

The literature review was an iterative process; the more I read, the more changes I needed to make to the parameters of the search. Clear points consistently emerged, such as:

- Nurses' knowledge and attitudes towards palliative care, particularly in hospital settings.
- Nurses' pain management in palliative care settings, especially in the community, oncology and surgical wards.
- Challenges and barriers to palliative care and the management of the associated pain experienced by the patients.

2.2 Search Strategy

I searched electronic databases, hand searched for relevant journals and explored Google Books. Studies that described nurses' experiences in palliative care were sourced from books, journal articles, newspaper articles and government documents. Titles and abstracts were screened for relevance. Further literature searches were carried out using CINAHL Complete, Clinicalkey Nursing Australia, The James Cook University One Search Engine, University of New England One Search Engine, Google Scholar and Google Search. Studies were viewed in full if they investigated the experiences of nurses in palliative care. Factors that appeared to affect the delivery of community palliative care were:

- Nurses' roles;
- Management of PLWHAs;
- Chronic illnesses;
- Pain management;
- Knowledge and attitudes to palliative care or pain management;

Due to the limited numbers of studies on community palliative care for PLWHAs, studies were included if they encompassed any caregiving of palliative care patients in regard to cancer management, or if they dealt with the care of PLWHAs in any setting. Most studies addressing pain management were found to describe research in the hospital setting, especially oncology units, with only a few related to community care. Most identified studies did not specifically examine PLWHAs and resulting chronic illnesses in the community, but did include some relevant aspects. The list of retrieved articles was then hand searched for further relevant papers. Due to a lack of studies addressing nurses' experiences delivering community palliative care to PLWHAs and resulting chronic conditions in Botswana, I extended my search to review African and international research, using the same processes.

2.3 Management of HIV/AIDS Patients and Related Chronic Conditions Through Community Palliative Care Initiatives

Although there is evidence that HIV/AIDS is declining or has stabilised in some Sub-Saharan Africa countries, its impact remains a major health challenge to families, communities and healthcare systems (Mangena-Netshikweta et al., 2012). HIV infection is a chronic illness requiring lifelong therapy, and is characterised by

multiple comorbidities. As such, it presents unique problems for healthcare delivery (Deeks et al., 2013; Simms et al., 2012). With many PLWHAs continuing to experience symptoms and complications that add to the burden of the disease across the spectrum of HIV diseases, there is a need to explore the role that early palliative care can play (Farber & Marconi, 2014; Simms et al., 2012). Palliative care, especially in Africa, has moved beyond the traditional hospice model and now predominantly relies on home-based care (Simms et al., 2012). Additionally, the ‘chronic disease’ approach to the management of HIV enables PLWHAs to address predictable challenges and sustain long-term care.

Providing palliative care to end-of-life patients is a difficult task, regardless of where it is needed (Harding et al., 2013b). It remains a central matter of concern for health policies in many countries (Ddungu, 2011). One on-going aim of healthcare systems is to ensure the provision of quality palliative care within all communities (Neergaard et al., 2009). The literature reveals that the number of PLWHAs and chronic illnesses needing palliative care in the community is escalating at an alarming rate (Connor & Sepulveda Bermedo, 2014; Uwimana & Struthers, 2007). For PLWHAs who have had access to Highly Active Antiretroviral Therapy (HAART), the HIV prognosis has changed from ‘terminal’ to ‘living with a chronic illness’ (Bader et al., 2006; Chin et al., 2006; Lowther et al., 2012). In resource-constrained countries, HIV-related cancers like Kaposi’s sarcoma have persisted in spite of ARV therapy; these are often not curable and require palliative care (Kell & Walley, 2009). PLWHAs required significant medical and nursing care and support. Unfortunately, many of their care needs have remained unmet (Jang & Lazenby, 2013; Uwimana & Struthers, 2007; Zerfu et al., 2012).

On-going palliative care is required to provide social, emotional and spiritual support for both the patients and families, from the time of diagnosis (Kaasalainen et al., 2011; Newbury et al., 2008). Kell and Walley (2009) conducted a qualitative study in Lesotho on palliative care in the era of ARV therapy. They reported that nurses felt that palliative care was necessary for HIV-positive patients despite the introduction of ARV therapy (Kell & Walley, 2009). In the United Kingdom (UK), Harding et al. observed that while ARV therapy was necessary, physical and psychological distress was not improved by it. They concluded that PLWHAs need on-going care (Harding et al., 2010).

Although there is increasing evidence for a link between HIV/AIDS and other chronic conditions, many authors did not link the care models (Lönnroth & Raviglione, 2008; van Olmen et al., 2012). As with most chronic illnesses, HIV/AIDS patients experience multiple symptoms from the disease itself, as well as side-effects from medications (Román & Chou, 2011; Selman et al., 2013; Simms et al., 2012). When chronically ill patients are released from hospital they often require on-going care (Mudanga et al., 2008; Pindani et al., 2013). Ddungu, (2011) and the European Association of Palliative Care, Connor & Sepulveda Bermedo, (2014) observed that in resource-constrained situations, home-based care is by far the most common model of palliative care provided. Selman et al. conducted a qualitative study on the palliative care needs and management of PLWHAs by HIV outpatient services (Selman et al., 2013). In total, 189 people were interviewed: 83 patients, 47 caregivers and 59 staff. Results indicated multiple challenges associated with living with HIV. The psychosocial distress of patients cared for in the community was exacerbated by loneliness and poverty, which had detrimental effects on adherence

to therapy. Selman et al. (2013) concluded that, as part of the palliative care approach, HIV care required holistic care and assessment that takes into account psychological, socio economic and spiritual distress, alongside improved access to pain relieving drugs (including opioids).

In many African countries, home-based palliative care entails the provision of care to HIV/AIDS patients and their families in their homes (Wesonga, 2015). Home-based care that includes palliative care is characterised as an alternative to traditional institutionalised care (Moetlo et al., 2011). It offers flexibility and increases the likelihood of the delivery of culturally appropriate care (Connor & Sepulveda Bermedo, 2014). It plays a significant role in improving the quality of life of individuals and families affected with HV/AIDS, and those living with on-going chronic illness (Wube et al., 2010). Although home care is considered ideal in most Sub-Saharan African countries, most families face social and economic challenges (Kang'ethe, 2009; Pindani et al., 2013; Selman et al., 2013).

Overall, the task of delivering care to PLWHAs and resulting chronic illnesses at home is immeasurably harder in resource-constrained environments, in which individuals are often medically underserved (Kang'ethe, 2014b). Issues such as poverty, isolation and an inability to satisfy basic living and health needs, as well as rejection by society, exacerbates the overall experience of PLWHAs in resource-constrained environments (Majumdar & Mazaleni, 2010). For obvious reasons, poor families have a reduced capacity to deal with the effects of morbidity and mortality. As a consequence of observing these experiences, PLWHAs are sometimes reluctant to seek services and support (Pindani et al., 2014). Studies show that in Africa, even though families are poor, most of the burden of managing PLWHAs and resulting

chronic illness falls on the practitioners of home-based care and the patient's family (Kang'ethe, 2014b; Majumdar & Mazaleni, 2010; Pindani et al., 2014). In South Africa, Peltzer and Phaswana-Mafuya found that 47% of HIV patients reported sometimes going without enough food, and 12% reported often going without enough food in the past 12 months. The chronic lack of adequate resources is thus a major obstacle in providing adequate palliative care to PLWHAs and other chronically ill patients in the community (Peltzer & Phaswana-Mafuya, 2008). In Malawi, Pindani et al.'s study of perceptions of people living with HIV and AIDS and home-based care concluded that PLWHAs in Malawi perceived home-based care to be beneficial, despite challenges such as lack of transport (Pindani et al., 2013).

The study of stigma as applied to PLWHAs has brought to light numerous complex issues, such as the importance of confidentiality, the management and consequences of secrecy, the biases within society and the health professions and the limits on people's expectations of care and pain (D'Cruz, 2004, p. 190). It is well-documented that many people would like to keep their health situations confidential, and that there are some illnesses such as HIV/AIDS for which the degree of confidentiality is higher than others (Bos et al., 2009). A study conducted in Lesotho by Makoae and Jubber focused on confidentiality and its effect on family caregivers for HIV/AIDS patients in home-based care (Makoae & Jubber, 2008).

The overall objective of this study was to analyse the challenges that family caregivers encountered in delivering home-based care, as they tried to access medical treatment for their family member in the context of confidentiality and limited medical care. Key results in this study revealed that when confidentiality was

adhered to, caregivers were frustrated by a lack of information, and experienced disrupted treatment. They found their opinions about the medical care of the patient were excluded, and that continuity of care was jeopardised. The authors argued that maintaining confidentiality in HIV/AIDS treatment in most African countries, which effectively excludes family members in the context of care, is a peculiar practice that contradicts the fundamental values of social cohesion (Makoae & Jubber, 2008). However, when most care is provided by family members, the concept of confidentiality is controversial. In the context of HIV, confidentiality was considered appropriate from the perspective of protecting PLWHAs from stigma (D'Cruz, 2004). In their Belgian study, Arrey et al. reported that HIV-positive Sub-Saharan immigrant women in Belgium hid their diagnosis from their intimate partners, children and caregivers to varying degrees. The reasons for keeping their status hidden included fear of disrupting relationships, violence, rejection and abandonment. These traumatic events were reported by a substantial proportion of participants (Arrey et al., 2015).

Zerfu et al. conducted a study on home-based care for PLWHAs in Arba Minch, Southern Ethiopia. The participants in the study complained about a lack of psychosocial support, and the social isolation resulting from the stigma associated with the HIV/AIDS diagnosis. The authors stated that the major drawback in the care and support for PLWHAs was poor referral and poor linkage to different organisations (Zerfu et al., 2012). Similarly, in a study from South Africa, dos Santos et al. reported that the experience of discrimination has been found to create severe psychological distress for sero-positive people and their families, causing isolation at a very trying and difficult period. Experiences of discrimination reported

by participants added to documented instances of enacted stigma within healthcare systems worldwide (dos Santos et al., 2014). Additionally, Wouters stated that PLWHAs who feared stigmatisation tried to embrace normal identities in encounters with their community, to hide their condition. They can only embrace the identity of an of an HIV patient on ARV therapy in the safe environment of their homes (Wouters, 2012, p. 373). Wouters (2012) concluded that PLWHAs on ARV therapy had to judge every situation and adapt accordingly.

2.4 The Role of CHB Nurses in the Delivery of Palliative Care

Given the shift of palliative care from hospital to home-based care, it is important to examine the role of community nurses (Kaasalainen et al., 2011). The role of nursing has been, and continues to be, integral to the delivery of community palliative care (Fitch et al., 2015), so nurses continue to provide the majority of hospice and palliative care services in the community globally (Clark, 2007; Payne et al., 2009; Payne et al., 2008; Simms et al., 2012). This shift has increased the responsibilities of community-based nurses. In Ontario Canada, Kaasalainen et al.'s study revealed that both rural and urban community nurses spent approximately 30% of their time providing palliative care, with managing pain being the most frequent area of involvement. However, they found that many barriers inhibited optimal symptom control in the community, resulting in unnecessary suffering and subsequent admission to hospital. The authors concluded that these findings had implications for the education of community nurses and the definition of community nursing roles (Kaasalainen et al., 2011).

Several studies provided a descriptive account of community-based nursing: they demonstrated how the caring role has evolved according to the needs of the community (Howell et al., 2014). They concluded that nurses must deal with increasing pressure to meet the demands of palliative care (Kennedy et al., 2015). Howell et al. interviewed community palliative care clinical specialists in the UK in order to describe their activities during interaction with patients. The study identified a wide breadth of activities carried out during the interactions with patients and their relatives and carers. The nurses provided multifaceted care, acting as liaison points to the complex health service across numerous healthcare settings (Howell et al., 2014). Balancing the need of patients and their families against the demands of the nursing role was a constant challenge in community palliative care nursing (Newbury et al., 2008). Robison et al. (Robinson et al., 2010) found that community nurses believed that, due to close-knit relationships in rural communities, palliative care was better coordinated there than in cities.

Nyakundi described the role of nurses as being the holistic provision of care, encompassing both physical and emotional care. In community, palliative care, nurses attempted to promote the highest standard of end-of-life care through community mobilisation and support for patients and their families (Nyakundi, 2013). In terms of clinical expertise, in situations where health workers and volunteers were utilised in home-based palliative care, nurses were required to provide support to and supervise other caregivers (Kingham et al., 2013; Nyakundi, 2013; Simms et al., 2012).

Verschuur et al. (2014) examined Dutch nurses' perceptions of proactive palliative care. The results indicated that nurses felt that an important part of their

job was advocating for patients and their families. As advocates, the nurses said they ensured that the patients understood the information provided by the doctors. In this role, the nurses supervised the quality and continuity of care (Verschuur et al., 2014). Van der Plas et al. observed that in the Netherlands, collaboration between district nurses and general practitioners was not always successful. Within home-care teams, caseload was usually high and teams consisted of less-educated practitioners, who may have found it difficult to communicate with doctors about palliative care (van der Plas et al., 2014).

An examination of the palliative care literature revealed that nurses are highly committed to their role (Harding et al., 2013a; Neergaard et al., 2009; Sandgren et al., 2007; Tomison & McDowell, 2011; Wallerstedt & Andershed, 2007). Broughton described community nurses' role as wide-ranging and diverse, and fulfilled a clinical and wider social care function. Through working in the community, Broughton found that the role allowed her to gain a clearer picture of community care perspectives, and offered an increased capacity to deal with hidden patient-related issues (Broughton, 2011).

Nurses needed to demonstrate equity in patient treatment and choices for patient care in their homes. The objective of Walshe and Todd's UK study was to explore how issues of equity and choice were put into practice by district nurses and other providers of community palliative services. The results showed that access to services, including district nurse services, was affected both by professionals' perceptions of their role and the way they worked with their colleagues. Nurses described offering different levels of care and responded to needs in an equitable yet individualised way. Such equality of care was seen as intrinsic to district nurses'

everyday work with patients, and allowed the nurses to view themselves as impartial, fair and just, despite the practical demands and resource constraints of their work. In contrast, the authors found that the patients did not see district nurses as providing equal service, because this perception depends on patients' knowledge about services and willingness to request care, which may not be the same across patients.

Additionally, inequalities may have had their source in the referral received, rather than how the nurses acted upon the referral. The authors further suggested that district nurses needed to be aware that some patients might find it difficult to initiate contact with services outside planned visits, even when the service was known to them (Walshe & Todd, 2011).

In some situations, community/district nurses found themselves dealing with unclear responsibilities without adequate support. Törnquist et al. found that although nurses had substantial levels of responsibility, they lacked support and did not have the necessary skills to deal with the intensive care required for dying patients. The authors concluded that nurses quite often had to deal with unclear responsibilities. The results highlighted the importance of recognising and acknowledging the required community nurses' knowledge and skill set (Törnquist et al., 2013).

Hope is necessary to keep nurses motivated and wanting to work in a challenging setting. In a qualitative Canadian study, Penz and Duggleby found that nurses described their hope as a positive state of being, involving realistic understanding. Their hope sustained and motivated them, helping them to strive to provide high-quality care (Penz & Duggleby, 2011).

The available literature suggested that one role of palliative care nurses dealing with death and dying involved providing bereavement support to families, for which they needed further training. Redshaw et al. surveyed Australian community nurses' experiences and perceptions of follow-up bereavement support visits. Responses from the community nurses suggested that this was an important role in their practice. However, half of the nurses reported that they found conducting follow-up visits difficult for various reasons, such as not being comfortable sitting with crying or distressed family members, or not having a clear understanding of what they hoped to achieve (Redshaw et al., 2013). Another Australian study found that nurses highlighted the value of the bereavement support visit (Chang et al., 2012). Nurses saw bereavement support as their role; however, they reported that managing emotionally intense episodes should receive priority when preparing community nurses for the role.

Nurses and other healthcare professionals recognise that planning for patients' discharge from hospital sets the stage for successful home care (Nosbusch et al., 2011). A UK study by Venkatasalu et al. described the views of stakeholders' and nurses' perceptions of nurse-led palliative care discharge services. The role of Macmillan Palliative Care Discharge Facilitators was found to overcome the barrier of late patient discharge to the community. Additionally, discharge facilitation by Macmillan nurses enabled patients to make informed decisions, increased access to available services and allowed nurses to act as a conduit between hospital and community (Venkatasalu et al., 2015).

2.5 Nurses' Pain Management of Palliative Care Patients

Pain management is an integral part of nursing, and nurses have a responsibility to effectively manage patient pain to maximise their comfort, but effective pain management does not always happen (Seyedfatemi et al., 2014). Spending time with patients and discussing their pain and how it can be reduced promoted a therapeutic healthcare professional-patient relationship (Grewal et al., 2012). Despite evidence that pain and suffering was known to afflict those with cancer, and that the later stages of AIDs were linked to highly painful experiences (Kingham et al., 2013), pain remained largely under-treated or untreated (Woodruff & Cameron, 2011). Managing pain has been reported to be stressful (Dunn, 2005; Mercadante et al., 2013; Rejeh et al., 2009a), and pain ranked among the most frequent complaints of terminally-ill patients (Daher, 2011).

While effective pain management is one of the fundamentals of palliative care, in Africa, late presentation, poor assessment skills, and poor availability of chemotherapy and opioids have impeded adequate pain control (Kassa et al., 2014; Onyekwa, 2011; University of Wisconsin-Madison. Pain and Policy Studies Group. WHO Regional Office for Africa (AFRO), 2013). People in Africa are more likely to seek treatment late in the course of the disease, hence presenting with severe pain (Kingham et al., 2013).

Many studies have examined nurses' knowledge of managing palliative patients' pain. Misconceptions about pain medications were identified among healthcare professionals. For example, a study conducted in India (Gielen et al., 2011), examined the attitudes of Indian palliative care nurses and physicians to pain

control and palliative care sedation. Nurses and physicians believed that pain killers (particularly morphine) hastened death; hence they were reluctant to dispense them. Home-care palliative nurses reported they were fearful of being wrongfully accused by family members, who maintained the conviction that painkillers hasten death. This study concluded that the administration of painkillers in doses that were not carefully titrated against the patient's pain was unnecessary and unethical. Similar findings were reported in Nigeria, where the use of analgesics (like morphine) in patients with chronic life-threatening conditions has always been misunderstood (Fadare et al., 2014). A further study in Iran confirmed that nurses were closer to the patients' pain and suffering, hence they were aware of ethical problems. The study revealed the need to review the curricula of healthcare professionals in order to emphasise palliative care, because there was a need for nurses to understand the use of opioids for patients experiencing severe pain (Virani et al., 2014). Another study undertaken in Ghana (Aziato & Adejumo, 2014) to determine nurses' level of knowledge of pain management revealed that nurses had an inadequate knowledge of this, which might be the result of gaps during training, as well as inadequate supervision.

A Jordanian survey (Al Qadire & Al Khalaileh, 2014) explored nurses' knowledge and attitudes regarding pain management. It found that Jordanian nurses lacked the knowledge to provide optimal pain management for patients, and also revealed a discrepancy between nurses' attitudes and their clinical practice, in which nurses were guided by their own biases when treating pain. Most nurses were reported to not treat pain, instead giving patients placebos or encouraging them to tolerate the pain (Al Khalaileh & Al Qadire, 2012).

Seyedfatemi et al. (2014) conducted a qualitative study in Iran to identify nurses' perceptions of palliative care for patients experiencing cancer pain. The study revealed that nurses believed that pain management for palliative care patients included treating both physical and psychological pain. However, the authors reported that nurses initially tried to discourage patients from taking opioids by talking about their side-effects. Although nurses showed that they were familiar with some aspects of pain management, they said they needed more knowledge about side-effects. This study indicated that there was potential to further explore nurses' understanding about use of opioids (Seyedfatemi et al., 2014).

Another study in Jordan produced similar findings. El-Rahman et al. (2013) compared knowledge and attitudes towards pain management between oncology and non-oncology nurses. Oncology nurses showed a better understanding of pain-management principles. The study concluded that the difference between the two groups might be due to their post-registration educational preparation on pain management. They concluded that experience and training improved knowledge and confidence for nurses delivering palliative care and pain management (El-Rahman et al., 2013).

Blondal and Halldorsdottir (2012) evaluated various methods for pain theory development. Their aim was to develop a model explaining nurses' complex pain-management task. They suggested that pain management must also have a strong link with theory, because theories serve as a broad framework for practice and may articulate the goals of the nursing profession and its values (Blondal & Halldorsdottir, 2012). A study undertaken in Ghana revealed that nurses had inadequate knowledge of pain management, which might have resulted from

curricular gaps during training and inadequate supervision (Aziato & Adejumo, 2014).

Lowther et al's (2015) study in Kenya found that a nurse-led palliative care programme for HIV patients on ARV therapy revealed that the nurse-led interventions were not effective in reducing pain. In contrast, person-centred assessment and care delivered by staff who had received additional training had positive effects on the mental health-related quality of life and psychological wellbeing of patients. While nurses were competent in dealing with physical symptoms, they were less competent addressing psychological issues. This could be because the treatment of the disease usually involved treating the related physical symptoms, while dealing with psychological issues may have involved assessing the mental status of the patient or dealing with family emotions and feelings for which the nurse did not feel prepared (Lowther et al., 2015).

In Iran, Iranmanesh et al. reported the experiences of Iranian oncology nurses. The study revealed that nurses adopted alternative ways of managing pain, such as being attentive to patients' pain by talking and listening to them. However, mental ambivalence among palliative care patients and their families remained a challenge of providing end-of-life care. As in many other studies on end-of-life care, nurses indicated that they were discouraged by the barriers to managing patients' pain, such as a shortage of nurses and heavy workloads (Iranmanesh et al., 2009).

Limited access to opioids was found to be one factor contributing to poorly managed pain. In Egypt, Alsirafy investigated the opioid needs of patients with advanced cancer, and the morphine dose limiting law in Egypt. The results showed that 117 out of 141 cancer patients were prescribed 420mg oral morphine per week.

The authors argued this dose did not provide adequate pain control, as patients still requested more pain relief. They also reported that the majority of patients did not even have access to oral morphine (Alsirafy et al., 2011). In Malawi, Tapsfield and Bates conducted a six-month review of hospital-based patients and their pain management. They concluded that, despite the fact that oral morphine was safe and cost-effective, it was still underutilised (Tapsfield & Bates, 2011). In most developing countries, patients only receive opioids while resident in hospital, and when discharged they lose access to them (Jang & Lazenby, 2013). Jang and Lazenby conducted a systematic literature review, the findings of which revealed that in Africa, opioids are easily accessed by hospitalised patients. They further highlighted that nurses' lack of prescription power is a compounding factor in the poorly managed pain of palliative care patients living in the community (Jang & Lazenby, 2013).

2.6 Nurses' Knowledge of Palliative Care

As the nurse's role is crucial to the delivery of palliative care in the community, it is important to understand the level of knowledge that nurses require to provide quality care. Several authors have documented inadequate knowledge in and education of healthcare professionals in symptom and pain management for palliative care patients (Brown, 2015; Paice et al., 2008; Virani et al., 2014; Zou et al., 2013). These studies stressed the need for further training and education of healthcare professionals, and the importance of ensuring that nurses have the right knowledge to effectively manage pain in the community. Brown observed that a poor knowledge base and lack of education opportunities in palliative care results in

suboptimal end-of-life care, and can be an obstacle to nurses' delivery of palliative care in the community (Brown, 2015).

The commitment to providing palliative care for all PLWHAs and patients suffering from related chronic illnesses could be fulfilled if health professionals, including nurses, were trained in palliative nursing (Aziato & Adejumo, 2014). In Japan, Nakazawa et al. reported that 85% of nurses were not aware of the physical symptoms of patients who required palliative care (Nakazawa et al., 2009).

A study conducted in Palestine to assess nurses' knowledge and attitudes towards palliative care found low scores in nurses' palliative care knowledge relating to pain and other symptom management and psychological and spiritual aspects. The nurses expressed discomfort when communicating about death. Nurses also scored low in perceived self-competence when providing pain management, and when addressing the social and spiritual domains of palliative care (Ayed et al., 2015). A similar study on knowledge and attitudes also revealed that nurses with high palliative care knowledge demonstrated positive attitudes (Nguyen et al., 2014).

Mahon and McAuley (2010) further revealed that nurses' understanding of palliative care is focused on symptom management, and that there is a gap in the holistic approach to palliative care. Their results documented that due to limited knowledge of palliative care, most nurses did not distinguish between palliative and hospice care, and believed that only patients near the end of life should receive palliative care. The authors concluded that the incomplete understanding of palliative care identified in their study was consistent with other studies (Mahon & McAuley, 2010).

A study conducted in Egypt revealed that the majority of nurses studied had not received any previous palliative care training (Morsy et al., 2014). The results of a cross-sectional study conducted in Addis Ababa by Kassa et al. indicated that two-thirds of nurses had poor knowledge of palliative care, and only half felt able to initiate discussion with patients about their diagnosis. Additionally, only one-third of nurses had good knowledge of palliative care (Kassa et al., 2014). In another study in Egypt, a survey was conducted to assess knowledge, attitudes and practices of nurses towards palliative care. It found there was a statistically significant relationship between nurses' educational level and their scores on the Frommelt's Attitude Towards Care of the Dying Scale, and that the more-educated nurses tended to have a more positive attitude towards the care of dying patients (Ali et al., 2010). Similarly, Zou et al. observed that in Mainland China, the palliative care education of health professionals mainly focused on curative care. Many health professionals had minimal knowledge of palliative care, and lacked knowledge and adequate skills to provide adequate pain and symptom control management (Zou et al., 2013).

Cumming et al. conducted a study in Australia to explore the experiences of PHC nurses in rural and remote New South Wales who provide palliative care as part of their generalist role. Remote and rural nurses identified pain and symptom management, as key educational needs. However, a majority of respondents indicated that there were significant barriers to education, such as isolation (Cumming et al., 2012).

2.7 Nurses' Attitudes Towards Working in Palliative Care with PLWHAs

There is a great interest in, and need to develop nurses' contribution to the care of stable PLWHAs through the provision of community (Tunnickliff et al., 2013). Providing nursing care to people in their home settings is now urgent (Ddungu, 2011; Stjernswärd, 2009). Therefore, it is important for healthcare system managers to understand what community nurses do when providing care to patients in their homes, in order to provide the necessary support. Community nurses get frustrated by the ambiguity of their role, which affects their attitudes towards the programme and patients. Studies have highlighted that nurses' positive attitudes and understanding of palliative care is key to providing quality care. To continue maintaining positive attitudes, nurses needed support and strategies to facilitate their encounters with patients and their relatives. Beck et al. described the experiences of providing palliative care to older people in a municipality context, and reported that nurses felt alone in caring for older people in their homes. They felt that they had no say in their organisation, and that their role was vague (Beck et al., 2012).

In their study in Ethiopia, Ali et al. reported that the majority of nurses had favourable attitudes and understanding of palliative care. The results suggested that although nurses had poor knowledge, they had good attitudes towards palliative care (Ali et al., 2010). Kassa et al. studied the assessment of knowledge, attitude, practice and associated factors towards palliative care among nurses working in selected hospitals in Addis Ababa, Ethiopia. They found that 76% had positive attitudes towards palliative care (Kassa et al., 2014).

Most community nurses find providing palliative care highly rewarding (Bliss & While, 2007; Burt et al., 2008; Sandgren et al., 2007). Although they sometimes feel undervalued in their role as key delivery agents of palliative care, they still take pride in providing that care.

2.8 Nurses' Stress in the Delivery of Palliative Care

Care for persons with advanced illness in the palliative care phase is complex and demanding, and influences the emotional wellbeing of healthcare staff. Those involved in prolonged care for terminally-ill PLWHAs experienced helplessness and emotional stress (Bam & Naidoo, 2014). Several authors suggested that caregivers and nurses working in palliative care settings are more at risk of stress (Ablett & Jones, 2007; Hawkins et al., 2007; Potter et al., 2010). Being a palliative care worker involves facing human suffering, dying and death, and nurses are affected by this (Beng et al., 2013; Johansson et al., 2011). Situations in which nurses were troubled were common in palliative care settings (Terakado & Matsushima, 2015).

Specific stressors found mainly in palliative care nursing have been reported to be associated with impending patient death and the relationship that has developed between the nurse and the dying patient (McCloskey & Taggart, 2010; Namasivayam et al., 2011; Pereira et al., 2012). Additionally, studies have shown that lack of support exacerbated the stress among palliative care nurses (Potter et al., 2010). Fillion et al. argued that organisational and professional demands on nurses providing palliative care have both physical and psychological effects on the nurses' ability to deal with human suffering (Fillion et al., 2009).

In research on medical professionals providing end-of-life care to cancer patients, Terakado and Watanabe reported a clear tendency for palliative care nurses

to feel more stress at their lack of competence at providing adequate palliative care (Terakado & Watanabe, 2012). White et al. argued that competency development among acute and critical care nurses has focused primarily on the provision of life-sustaining care and less on the care of the dying. Experienced nurses found symptom management, including pain management and communication about death and dying, more important than less experienced nurses. Less experienced nurses were more concerned about dealing with their own feelings about death and dying (White et al., 2014).

Evidence for stress among nurses working in palliative care was mixed and may be related to structural factors more than the difficulties of working with patients (Pereira et al., 2012). In Malaysia, Beng et al. found that the lack of resources and staffing affected how nurses delivered palliative care, resulting in stress. The failure to attend to patients due to staffing problems was a source of stress for nurses (Beng et al., 2013).

In a study in South Africa, Uren and Graham demonstrated different dimensions of coping with caregiving. Caregivers and nurses found it hard to live with the stress caused by high workloads and inadequate resources. The participants described high workload as their most stressful challenge (Uren & Graham, 2013). In their study in Japan, Terakado and Matsushiba showed that stress among palliative care nurses engaged in palliative care in general wards was predictable, based on the level of fatigue and their level of coping, emotionally. The authors reported that nurses experienced a high degree of both mental and physical fatigue (Terakado & Matsushiba, 2015). In Sweden, Johansson et al. concluded that creating an excellent palliative care work environment can serve as a buffer against stress among nurses

(Johansson et al., 2011). An environment in which nurses feel supported was considered important to reducing stress (Terakado & Matsushiba, 2015).

Other researchers who have examined stress levels among nurses providing palliative care have reported that nurses experience 'moral distress' due to the lack of resources allocated to the patients' wellbeing (Fournier et al., 2007; Harrowing & Mill, 2010; Pereira et al., 2011). Moral distress is defined as the:

Pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility and makes a moral judgement about the correct action, yet as a result of real or perceived constraints, participates in wrongdoing. (Rushton et al., 2013,p. 1074)

Nurses, being the professionals who provide the most care to terminally-ill patients, experience high levels of emotional exhaustion and moral distress (Ablett & Jones, 2007). Rushton et al. developed a framework for understanding moral distress among palliative care clinicians. The model was aligned to four dimensions: empathy (emotional attunement), perspective taking (cognitive attunement), memory (personal experience) and moral sensitivity (ethical attunement). They suggested that these dynamically intertwined dimensions create preconditions for how clinicians respond to a triggering event (Rushton et al., 2013,p. 1074). Fournier et al. further report that moral distress experienced by nurses led to a high workplace turnover of nurses (Fournier et al., 2007).

In an ethnographic study on nurses' moral distress and cancer pain management, the authors found that nurses were distressed when they witnessed patients suffering from untreated pain, and that nurses were worried that family may

attack or blame them if a patient died suddenly in the ward. Discussing the prognosis with the family was another source of worry, as patients feared doctors, and nurses were helpless in the management of cancer and pain (LeBaron et al., 2014). Nurses experience moral distress when they are conscious of the appropriate moral actions to take but are prevented from carrying them out due to institutional barriers (Rejeh et al., 2009b).

2.9 Shortage of Nurses and Effects on the Delivery of Community-Based Palliative Care

2.9.1 Worldwide

The shortage of nurses around the world has had a hugely negative impact on the health and wellbeing of populations (Buchan & Aiken, 2008; Littlejohn et al., 2012). This shortage is a global problem, but in low and middle-income countries the crisis is acute (Callaghan et al., 2010; Ochieng et al., 2014). The demand for nurses continues to grow due to the increase in NCDs. According to the WHO, a shortage of trained health professionals in rural areas is common in both developed and developing countries (World Health Organization, 2010b). Globally, rural areas are served by 38% of the total nursing population, while 62% of nurses serve urban populations. Less than 25% of physicians serve rural populations (World Health Organization, 2010). The ideal numbers for the delivery of adequate health services are at least 2–3 well trained healthcare providers per 1,000 people, to reach 80% of the population (World Health Organization, 2006).

2.9.2 Africa

Studies have revealed that Sub-Saharan African countries have the most extreme shortage of nurses (Naicker et al., 2010; Scheffler et al., 2009). Kinfu et al.

found that training capacity in 12 African countries was insufficient to maintain the absolute number of health professionals. The results from the 12 countries showed that for every 1000 practicing physicians, 59 medical graduates were produced each year, and 66 nurses and midwives per 1000 population were produced annually (Kinfu et al., 2009). Additionally, Naicker et al. conducted a literature review of 47 countries in Sub-Saharan Africa and found that there were two doctors and 11 nurses/midwives per 10,000 population (compared to 19 doctors and 49 nurses/midwives per 1000 Americans), and 32 doctors and 78 nurses/midwives per 10,000 population, with an estimated 1.1 million doctors, nurses, midwives and other health workers needed (Naicker et al., 2010). Several authors describing staff shortages in Africa have stated that low pay from governments and the private sector, attrition due to HIV/AIDS, limited career progression and poor work environment, including poor infrastructure, all contribute to poor retention of skilled health workers (Kinfu et al., 2009; Littlejohn et al., 2012; Munjanja et al., 2005; Tshitangano, 2013). Similarly, Mokoka et al. concluded that South Africa was experiencing a serious shortage of nurses. The results of their studies were consistent with other studies, concluding that it is difficult to retain nurses due to poor working conditions, excessive mandatory overtime and the unsatisfactory physical state of hospitals. Compounding these shortages was the high rates of HIV/AIDS infections experienced by health staff themselves (Mokoka et al., 2010).

The migration of health professionals from their home countries to developed countries has had an effect on healthcare systems as well, and has exacerbated the shortage of skilled human resources in developing countries (Li et al., 2014; Naicker et al., 2010). The inter-country recruitment and migration of nurses from developing

to developed countries has made the nursing shortages experienced in Sub-Saharan Africa more acute.

2.9.3 Botswana

A shortage of trained and qualified health professionals in Botswana remains one of the major bottlenecks, which impede the delivery of quality healthcare (Botswana Ministry of Health, 2010b). As a result of HIV/AIDS and other chronic illnesses there is increasing demand on the already overstretched skilled workforce (Ama, 2011; Bodilenyane & Motshegwa, 2012b; Botswana Ministry of Health, 2010b). Botswana supplied four physicians and 27 nurses per 10,000 people, contributing to the challenges in offering palliative care (Malik, 2013). The United Nations Human Development Report (p. 120) reported that ‘recent estimates indicate that there is a global shortage of 13.6 million care workers’ (United Nations Development Programme, 2015). Botswana’s shortage of healthcare workers is worse in rural and remote areas, as in other countries (Nkomazana et al., 2015).

Several studies have documented the shortage of nurses in Botswana (Kinfu et al., 2009; Liese & Dussault, 2004; Nkomazana et al., 2015; Nkomazana et al., 2014; Sinha & Onyatseng, 2013). In their study on stakeholders’ perceptions on healthcare worker shortages in PHC in Botswana, Nkomazana et al. (2015) identified multiple factors that undermine the effectiveness of human resource management in Botswana, including unattractive and non-competitive incentives and remuneration packages compared to those in neighbouring countries, such as Namibia and South Africa. The inequitable distribution of nurses favouring urban hospitals has resulted in higher attrition rates in rural and remote areas. The lack of adequate training

institutions means that health professionals have sought training abroad, resulting in the majority of graduates remaining out of the country after graduation.

Nkomazana et al. (2015) suggested that weak and sometimes incompetent healthcare and human resource management characterised by lack of essential resources for patient care, poor career structures, unclear policies, absence of support supervision as well as poor working conditions were among the major contributing factors for the migration of Botswana nurses. Weak and inadequate incentives and low salaries are known to be strong factors for migration of health professionals (Bodilenyane & Motshegwa, 2012a, 2012b; Nkomazana et al., 2015; Thupayagale-Tshweneagae, 2007).

2.9.4 Task shifting for nurses in community palliative care

Task shifting has been defined as the rational redistribution of tasks among health workforce teams (Dambisya & Matinhure, 2012), such as when a less-qualified professional takes on some of the roles and responsibilities of a more qualified health professional (World Health Organization, 2008). Task shifting exists as a successful model to scale up services where human resources for healthcare are limited (Barken et al., 2015; Callaghan et al., 2010; Crowley & Mayers, 2015; Ledikwe et al., 2013). The strategy has been advocated as a way of addressing shortages of health professionals in resource-constrained countries (Barken et al., 2015; Bemelmans et al., 2015; Fairall et al., 2012; O'Malley et al., 2014; Selke et al., 2010; World Health Organization, 2008). Task shifting has resulted in nurses having to manage less-trained personnel in performing their tasks, while nurses perform some of the doctors' tasks, such as consultation and prescription of medications

(Dambisya & Matinhure, 2012; Fairall et al., 2012; Mdege et al., 2012; O'Malley et al., 2014).

Shifting tasks to community health workers has provided an added benefit without compromising care outcomes (Crowley & Mayers, 2015). Regardless of health workers' levels of knowledge, they have provided some essential services not easily delivered by the clinics, such as adherence and psychosocial support (Ivers et al., 2011). Crowley and Mayers reported that task shifting is an effective strategy for addressing human resource shortages in resource-constrained countries in Africa. However, they found challenges to its adoption, including inadequate supervision and mentoring of health workers (Crowley & Mayers, 2015). Similarly, in Swaziland, Mehlomakhulu et al. reported that the concept of task shifting has been embraced by the Swaziland MoH. This was demonstrated by the shifting of some tasks from one category to another in response to the workload created by HIV and its co-infections. However, the limited number of doctors at health institutions often left nurses with no choice but to carry out tasks not normally undertaken by doctors (Mehlomakhulu & East, 2010).

There is evidence that task shifting has worked in some developing countries with HIV/AIDS programmes that are rolling out of ARV therapy (Fairall et al., 2012; Ledikwe et al., 2013; Uebel et al., 2011; Zachariah et al., 2009). In a study on task shifting ARV therapy from doctors to nurses in South Africa, Fairall et al. evaluated the effectiveness of ARV therapy initiated by nurses in comparison to doctors, and found that employing nurses to initiate ARV therapy improved survival rates (Fairall et al., 2012). In Malawi, Zachariah et al. reported that non-physician clinicians providing ARV therapy made it possible to scale up the ARV therapy with

acceptable quality standards (Zachariah et al., 2009). Evidence from Malawi, South Africa, Uganda and Botswana has shown that decentralisation and task shifting in the distribution of ARVs has worked in scaling up the therapy to rural settings (Jaffar et al., 2010; Miles et al., 2007; Zachariah et al., 2009). Another study in South Africa explored task shifting practices in ARV treatment. The study reported that nurses spent considerable time on training, counselling and administrative tasks that could be shifted to HCWs, to leave room for nurses to engage in clinical practice (de Wet et al., 2011).

Lay health workers are also used in many countries in Sub-Saharan Africa to mitigate HIV/AIDS, but their use can be only successful when accompanied by training and support. In a study evaluating the task shifting initiative of lay counsellors in Botswana, Ledikwe et al. showed that lay counsellors were comfortable with their duties, even clinical duties beyond their official level of competencies. However, lay counsellors' training is not comprehensive and does not adequately cover some aspects of their practice. The authors conclude that lay counsellors are fulfilling an important role; however, there is a need to address the knowledge gaps identified (Ledikwe et al., 2013).

Ochieng et al. conducted a study in Kenya on the perceptions of health stakeholders on task shifting and the motivation of community health workers. The participants agreed that promotional and preventative activities, including simple curative tasks, could be shifted to CWHs, as detailed in Kenyan policy. However, due to the lack of access to care caused by large distances and lack of trained healthcare professionals, the researchers found that nomadic and peri-urban health workers had assumed curative services beyond their scope of practice within task

shifting. The study concluded that it was inevitable to allocate curative tasks to the community health workers, but raised issues relating to the need for accreditation and regulation of their tasks (Ochieng et al., 2014). Task shifting has also reduced the number of visits and the time spent by regulated healthcare professionals visiting patients in Uganda (Babigumira et al., 2009).

2.10 Nurses Working with Families in Community-Based Palliative Care

2.10.1 Worldwide

Nurses are important in providing support to families during palliative care. Comforting patients and their families is one of their most difficult and important roles. It helps patients and their families accept and deal with the situation. Nurses will often spend much of their time working with families (Kirby et al., 2014), and can attach meaning to the process of caring for patients at the end of their life (Baliza et al., 2012). The ability of families to assume caregiving responsibilities is dependent on the professional guidance and support they receive from healthcare professionals (Baliza et al., 2012).

Van Rooyen, Le Roux and Kotze examined the experiences of oncology nurses and concluded that oncology nurses attending to cancer patients and their families experienced unique challenges, including dealing with interpersonal relationships (Van Rooyen et al., 2008). Nurses also acted as mediators during moments of anxiety or distress (Broom et al., 2015). Anwar et al. argued that at times, nurses' roles involved them in familial conflicts, which was difficult for them because they wished to remain neutral (Anwar et al., 2013). Such dynamics can produce stress and burnout among nurses providing palliative care. They may

become exhausted and overwhelmed (Bam & Naidoo, 2014), and find it hard to deal with family members' feelings during early stages of care. According to Anwar et al., family members of patients experiencing long-term or end-of-life care express loss in different ways, some which were difficult for healthcare professionals to handle (Anwar et al., 2013).

For many families, the diagnosis of a family member with a life-threatening illness was a major confrontation resulting in physical, emotional and financial stress. In this context, managing and displaying appropriate levels of emotion was a core feature for nurses (Bailey et al., 2011). Kirby et al. conducted a qualitative study in Australia on nurses transitioning patients from curative to palliative care. They indicated that although nurses talked extensively about their interaction with patients transitioning to palliative care, each emphasised that families presented some challenges during transition (Kirby et al., 2014).

Walshe and Luker found that nurses understood compassionate comfort care and articulated the significance of effective supportive communication with patients and families (Walshe & Luker, 2010). In Canada, McLeod et al. observed that the sense of being known by the nurses was identified by families as helpful for negotiating the cancer experience, particularly in managing difficult transitions and dealing with bad news. The authors concluded that engagement with families reflected a commitment to continuing and fostering a relationship (McLeod et al., 2010).

To provide quality care to patients, nurses must communicate effectively with families. In their US study, Boyle et al. found that patients and families required nurses who were sensitive to their needs (Boyle et al., 2005), while caring for the

sick family member (Maddalena et al., 2012). In another US study, Curtis et al. found that improved communication with family members of critically ill patients could decrease the emotional distress that occurred among family members regarding death and dying issues. However, communication was an on-going challenge for staff working with people facing life-threatening illnesses and their end-of-life. Unclear communication could lead to discrepancies in patient care between the healthcare providers and families (Curtis et al., 2005).

Palliative care nurses enacted various roles, including conveying sad news such as the incurable nature of the illness and inevitable death (Higginson & Costantini, 2008). In most Asian cultures, the primary decision-makers are male members of the family, meaning decisions are gender-skewed, with males having a predominant voice. For example, in India, Chaturvedi reported that the family played a significant role in each stage of disease management, and a male family member was the decision-maker, a practice that impeded the activities of health practitioners (Chaturvedi, 2008).

2.10.2 African context

Palliative care is morally prescribed by the nursing profession (Zuzelo, 2007). Nurses are expected to comply with the wishes of the patients and their families, even when these values may not be in agreement with their own views (Bam & Naidoo, 2014). In Africa, Downing reported that belief still persists in witchcraft and traditional medicine, particularly in rural areas (Downing, 2007). Many patients consult traditional healers before visiting the hospital (Babb et al., 2007; Peltzer et al., 2006). This has implications for how nurses work with families. Levers argued that the cognitive orientation of a particular culture remains important

to how members of the culture make meaning in their lives (Levers, 2006). In addition, Kangethe posited that traditional medicine is profoundly embedded in the beliefs and values of each community (Kang'ethe, 2009).

However, in the context of HIV/AIDS, despite the increasing availability of ART only a small proportion of eligible needy patients have accessed the treatment (Madiba & Langa, 2014). Due to the high cost and scarcity of ART in many African countries, many PLWHAs turn to traditional healers (Agbor & Naidoo, 2011). Traditional healers are accessible, affordable and culturally acceptable (Kangethe, 2009). In a study on the use of traditional medicine by HIV infected individual in South Africa, Babb et al. found that 84% of patients reported using traditional medicine at some point during their illness. Forty four percent were using traditional medicine during the study period, and 23% who were on ART reported also using traditional medicine simultaneously. The authors concluded that the use of traditional medicine is common among HIV infected individuals. However, they further observed that simultaneous use of ART and traditional remedies has the potential for drug interaction (Babb et al., 2007). Kangethe (2009) observed that, if not closely monitored, the concurrent use of ART and traditional medicine could interfere with the efficacy of ART. Therefore, nurses have a duty of care in monitoring the use of both regimes. This can present an ethical dilemma for nurses, and promote a conflict of interests. Payne maintained that although nurses play an important role in providing support to palliative care patients and their families, primary care has been shaped by cultural factors (Payne et al., 2009).

An evaluation of palliative care in Uganda, Kenya and Malawi by Grant et al. reported that, due to cultural factors and male-dominated/patriarchal beliefs, some

female PLWHAs have been rejected, ostracised and isolated, even when they needed care. They also observed that, due to traditional beliefs, most patients consulted traditional healers, and that consequently patients presented late in their disease progression (Grant et al., 2011).

A study in South Africa found that palliative caregivers who are part of the community did not want to be seen as trespassing upon cultural beliefs, and were therefore reluctant to speak about impending death in the family (Campbell & Amin, 2012). In Zulu and other African cultures, speaking about death means that one is confirming or predicting a death in the family. This could have a psychological impact on the patient and the family (Kassa et al., 2014). In contrast, De Kock found only 24% of South African nurses were uncomfortable talking about death and dying. Working with patients who did not benefit from treatment and who were facing death could result in frustration for nurses, and this situation could inhibit communication with the family about the inevitable death (De Kock, 2011).

Nurses' comprehension of and improvement in communication about end-of-life events is fundamental to improving the care of patients at home. Nurses working in palliative care habitually encounter patients and relatives struggling with feelings of grief and uncertainty. Campbell and Amin argued that one of the most distressing tasks for nurses in rural South Africa was telling patients that they had an incurable and life-limiting disease (Campbell & Amin, 2012). Portenoy stated that:

Communication between patients, family and health professionals can be limited, inaccurate or constrained by cultural expectations. This can lead to uncertainty about the goals of care, absence of advanced care planning, problems in care and coordination or high caregiver burden (Portenoy, 2011, p.2236)

In their study investigating the perceptions of PLWHAs regarding the delivery of home-based care in Malawi, Pindani et al. found that the task of delivering home-based care to PLWHAs was mainly left to family members, with health workers and volunteers only visiting to supplement the tasks conducted by family members. The study concluded that families who provided care to PLWHAs needed assistance with the delivery of physical care (Pindani et al., 2013).

2.11 Importance of Family in Botswana Healthcare

Due to the increase in the number of PLWHAs and the high prevalence of related chronic diseases in Botswana, the number of patients in need of palliative home care will continue to increase (Jang & Lazenby, 2013; Livingston, 2004). Family and community palliative caregivers have performed a variety of roles to help home-based care patients: relieving symptoms including pain and providing emotional support (Kang'ethe, 2006). Reflecting on the strong and extended family structure typical of most African countries, it is not surprising that most patients prefer to receive palliative care at home. In their study on place of death in Botswana, Lazenby et al. confirmed that older people were likely to die at home (Lazenby et al., 2010).

Holman found that while many AIDS-related illnesses are controllable once diagnosed, individuals often live with pain and a diminished quality of life, needing on-going care at home (Holman, 2005). Sabone found that, in the event of being faced with the terminal illness of a family member, families were affected in many ways: physically, emotionally and financially. Therefore, there was a need for a trusting and open relationship with nurses (Sabone, 2015). As in much of Africa, provision of care to Botswana PLWHAs in the community has put an extraordinary demand on families, who have needed extended support from the healthcare system (Lazenby & Olshvevski, 2012). With the increase in HIV/AIDS, families will continue to care for their dying family members. AIDS has created a shift in roles in Botswana, as elderly people are now caring for their adult children as well as their grandchildren (Lazenby & Olshvevski, 2012). Sabone (2015) observed that in Botswana, AIDS has transformed life experiences and the whole social structure has been shaken.

Nurses caring for patients at home have had to learn to interpret and understand family dynamics and respond accordingly (Dintwat, 2010; Livingston, 2004). This has enabled nurses and volunteers to develop a good working relationship with the families and relatives of patients. To further improve relationships, attempts have been made to incorporate the family care model into home-based care, and to train nurses on the best possible ways to communicate with families (Mudanga et al., 2008). In Botswana, volunteers who worked with families stated that even though they were allowed entry into the family, some families considered things such as bathing the patient to be intimate, and therefore the family's responsibility (Shaibu, 2006). Their experiences dealing with families were

not easy, and there were occasions when families declined their presence, as they had changed their minds about the proposed treatment. Their most frustrating situation was dealing with families regarding conflicts with traditional healers and the use of traditional medicine.

Chipfakacha maintained that Batswana have traditionally consulted traditional healers at some point during their illness (Chipfakacha, 1997). Traditional medicine is usually recommended by a traditional healer or a spiritual healer (Kang'ethe, 2009; Madiba & Langa, 2014). Findings from a study by Madiba and Langa in Botswana revealed that, even though there were some positive attributes to traditional therapies, traditional practices were characterised by misconceptions (Madiba & Langa, 2014). In a study in Thamaga village in Botswana, Bene and Darkoh found that traditional doctors encourage utilising a combination of traditional herbs with ARV therapy to their patients (Bene & Darkoh, 2014).

Kangethe reported that intergration of traditional healers into modern health raises challenges, because African traditional healers use rituals containing some unacceptable practices. He further argued that because most traditional healers were not trained, they can, for instance, employ the use of unsterile razor blades to introduce medicines into the blood stream and thus cause significant harm (Kang'ethe, 2014a). He concluded that collaboration with traditional health practioners is key to improving their understanding of biomedical issues. Kangethe stated that concerns over the moral and ethical approaches associated with the healers' therapies, their hygiene, their anatomical and physiological knowledge to effect diagnosis, and the fact that they want to keep the information about some of

their herbal concoctions secret to themselves calls for a change (Kang'ethe, 2014a, p.76).

2.12 Chapter Summary

This review of the literature has identified a number of key issues related to the experiences of nurses providing palliative care to PLWHAs and related chronic conditions in Botswana. The review explored a broad spectrum of nurses' experiences in providing palliative care. The literature examined was not limited to Botswana because not many studies have specifically been conducted in Botswana. However, the literature on Botswana has identified that the provision of palliative care is a challenge to healthcare providers due to lack of resources, and nurses' role in the provision of palliative care is ambiguous.

As the nurse's role is crucial to the delivery of palliative care in the community in Botswana, it is important to understand the factors that contribute to the effective delivery of that care. In most community clinics in Botswana, particularly in remote areas, nurses are the only health professionals in the community, meaning it is their responsibility to make important decisions related to palliative care, such as selecting patients for ARV therapy. They were also required to provide guidance to other health workers, families and volunteers in the implementation of services related to palliative care (Bodilenyane & Motshegwa, 2012a; Botswana. Ministry of Health & Botswana. Department of HIV/AIDS Prevention and Care, 2013; Jimbo & Botswana. Department of HIV/AIDS Prevention and Care (DHAPC), 2005; Livingston, 2004)

A shortage of nurses has affected the delivery of services throughout Sub-Saharan Africa, as has the lack of opioids. Most studies concluded that nurses

working in palliative care in Africa and other resource-constrained areas experienced stress and burnout due to the lack of adequate resources.

With limited knowledge on palliative care and pain management, nurses in palliative care settings struggle to communicate effectively with patients and their families, especially when conveying sad news such as a life-threatening diagnosis. As a significant gap in the literature of palliative home care for PLWAs was identified, this study was undertaken to document the experiences of community-based home-care nurses in Botswana. The next chapter provides an overview of the methodology and methods of this study.

Chapter 3: Methodology and Methods

3.1 Introduction

Interpretive hermeneutic phenomenology, an approach to qualitative research now widely used in health research, was chosen for this study. This chapter discusses why this approach was considered the most appropriate. It explores the origins of phenomenology, Husserlian phenomenology and bracketing, Heidegger and the hermeneutic approach, contrasting perspectives in the hermeneutic approach, the development of hermeneutics and how van Manen clarifies hermeneutics. The selection of van Manen's hermeneutic technique as appropriate to the study, and the application of his guidelines to the analytic process, is explored. Ethical considerations and the need to establish local approval for the project are examined. Finally, the processes of data collection and analysis are discussed.

Phenomenology is the study of lived experiences of the life world (van Manen, 1990). Hermeneutic phenomenology uncovers concealed meanings embedded in the narratives of participants. Van Manen's (1990) hermeneutic inquiry aimed to describe phenomena as they present themselves to the consciousness. This process is appropriate to this study as its objective was to allow the nurses to reveal the nature of the challenges they experience while providing palliative care to HIV/AIDS patients being cared for in the community in Botswana. Further, the study sought to understand how nurses viewed their role in the delivery of such care.

3.2 Research Design

Phenomenology is useful when the researcher seeks to find the meaning of occurrences within a lived experience (van Manen, 2007), and is therefore

appropriate to this study. The focus on lived experience is central to phenomenological inquiry, as its aim is to recognise a phenomenon before it is conceptualised, abstracted or theorised (van Manen, 2014). Van Manen (2014, p. 200) explained that phenomenology aims ‘to describe and interpret the lived world as experienced in everyday situations’. This study included interviews conducted with 13 nurses working in community settings in 12 districts in Botswana. Audio-taped interviews were recorded and transcribed before analysis. Transcripts of the interviews were subjected to phenomenological thematic analysis using van Manen’s (1990) approach.

3.3 Research Aim

The aim of this study was to explore the phenomenon of providing home-based care to PLWHAs in Botswana from the perspective of nurses delivering palliative care.

3.3.1 Research question

What is the lived experience of nurses delivering palliative CHBC to PLWHAs in Botswana?

3.3.1.1 Sub-questions

- Has caring for PLWHAs and those suffering from resulting chronic conditions in the community changed the way nurses deliver community-based palliative care in Botswana?
- How does caring for PLWHAs in their homes affect the nurses?
- How effective do nurses believe their symptom and pain-management techniques are when delivering palliative CHBC in Botswana?

3.4 Background to the Research

HIV/AIDS has had a huge impact on the management of people with chronic illnesses and has led to the establishment of palliative and community palliative care programmes in Botswana (World Health Organization, 2010a). It has affected nursing practice and the role of nurses and other health professionals in Botswana. Given the extent of this impact, there has been a need to investigate Botswana nurses' experiences of managing these terminally-ill patients in the community.

The task of managing chronically ill people in the community has been greatly exacerbated by the severity of the HIV/AIDS epidemic and the erosion of traditional extended family structures in Botswana. Traditionally, families were available to assist in the care of sick relatives (Phaladze et al., 2009; Shaibu & Phaladze, 2010), but this is no longer the case as many relatives have themselves died from HIV/AIDS. Much of the care of chronically ill people has become the responsibility of CHBC nurses. In the literature review, no study was found in Botswana that addressed this issue. The aim of this study was therefore to understand the experience of caring for terminally-ill PLWHAs, and those suffering from resulting chronic illnesses, in the community setting in Botswana. The findings from this study will be disseminated to inform government policy in Botswana and improve community palliative care services, particularly the management of pain and other debilitating symptoms associated with HIV/AIDS. Also, it is hoped the study findings will assist in the development of community support structures for healthcare providers, including development of volunteers' role in the care of people with HIV/AIDS and comorbid chronic illnesses.

3.5 Selection of the Phenomenological Approach for this Study

To conduct a phenomenological research project of this nature, it was necessary to seek an understanding of nurses' experiences of caring for PLWHAs who are managed in a community setting. Giorgi and Aanstoos maintained that if the researcher wants a subjective comprehension of the experience of the phenomenon from the participants' viewpoint, a new process is needed (Giorgi & Aanstoos, 2000). The goal of this research was to describe the lived experiences of nurses in a way that communicated the essential meaning of the experiences. Phenomenological research entails exploration of the composition of the human life world, as experienced in everyday situations (van Manen, 1997, 1990).

According to Hein and Austin (Hein & Austin, 2001) there is no singular way to conduct a phenomenological study, as they embrace different meanings depending on the context of the phenomena being studied (Adams & van Manen, 2008). The specific method used by the researcher depends on the purpose of the study, the researcher's skills and the nature of the research question (van Manen, 1997). The researcher must contextualise phenomenological research into the philosophical context that informs its method, employing techniques such as those created by Heidegger, Husserl and Merleau-Ponty (Flood, 2010; Koch, 1995). Van Manen's approach was used here because he reminds us that 'phenomenological research makes a distinction between appearance and essence, between the things of our experience and that which grounds the things of our experience' (van Manen, 1990, p. 32). His approach to phenomenology centres on the fact that people live in a world of experience, subject to both cultural and social influences (Caelli, 2000;

Flood, 2010). The epistemology of phenomenology is focused on revealing meaning rather than on arguing a point or developing a theory (van Manen, 1997), an approach aligned with other qualitative methodologies.

Phenomenology does not produce new information, but rather appropriates and interprets the meaning that already exists in the lived experience (Burch, 1990). Van Manen (1990) states that phenomenology offers insights that help bring us into direct contact with the world, and assists us to uncover the meaning of lived experience from those who understand that experience. This aspect of phenomenology is appealing because of nurses' experiences in Botswana, as detailed below.

Phenomenology as a philosophy and a research method seeks to describe experiences as they are lived. It is a scientific inquiry concerned with the study of human experiences and perceptions (Byrne, 2001; van Manen, 1990). Phenomenology describes the structure of various types of experience, ranging from thought and perception through to emotions. Willis suggests that it should be made clear at the onset of a phenomenological study that researchers are dealing with people not objects, and that a person is viewed as a whole entity, imbued with past experiences (Willis, 2001). Further, as phenomenology seeks to find the meaning of the occurrences within lived experiences, van Manen (1997, p. 1844) states that 'phenomenology must describe what is given to us in immediate experience without being obstructed by "preconceptions" and theoretical notions'. The researcher must recognise that the participants' experiences are paramount in phenomenology (van Manen, 2007).

3.6 Origins of Phenomenology

Several researchers and philosophers, concerned that positivism as a method of inquiry was inadequate for the study of human phenomena, believed that a new method of inquiry was necessary (Byrne, 2001; Gummesson, 2000). In contrast to positivist approaches, phenomenologists believed that a researcher cannot be detached from his/her assumptions (Colaizzi, 1978). Positivists view reality as something out there to be apprehended; they assume that the world is structured in generalisations that can be identified and predicted to generate results or outcomes (Munhall, 1989). Denzin and Lincoln state that positivists/post-positivists ‘work from within a realist and critical realist ontology and objective epistemologies, and they rely on experimental, quasi-experimental, survey approaches to research’ (Denzin & Lincoln, 1998, p.13). Increasing dissatisfaction with positivist methodology led to the development of post-positivist methodologies, which were deemed more relevant to research in the humanities, social sciences, health and education (Lincoln & Guba, 2000).

Phenomenology is a qualitative approach widely used across the health sciences, including nursing (Converse, 2012), and is a philosophy, approach and method of human science research (Heinonen, 2015). As a method of enquiry, it enables researchers to reclaim that part of human experience that may be neglected in the more positivistic approaches to research (van Manen, 1990). The main concepts in phenomenological research are the development of the understanding of meaning, and the study of some human concerns, lived experiences, life worlds and reduction (Heinonen, 2015). However, van Manen points out that phenomenological

philosophers are diverse in their interests and their interpretation of issues (van Manen, 2007).

3.7 Early Phenomenology: Husserl and ‘Bracketing’

The origins of phenomenology lie with German philosopher Edmund Husserl (1859–1938) (Kakkori, 2010). He developed a concept of phenomenology as a new method destined to supply a new foundation for both philosophy and science (Kakkori, 2010). Patton pointed out that Husserlian phenomenology was guided by how people describe and experience things, and his philosophical assumption was that we could only know what we experience through our own perceptions and meanings (Patton, 2002). Husserl’s focus was on the study of phenomena as they appeared through consciousness, and he rejected the belief that objects in the external world have independent existence (Lavery, 2003). Husserl’s belief was that consciousness forms the basis of all understanding, and it plays a central role in the meaning given to the phenomena under study.

According to Husserl, essential being must be distinguished from actual existence, just as the pure ego must be distinguished from the psychological ego. Essences are non-real while facts are real. Husserl’s movement in classical phenomenology was from the real to the abstract. To grasp the essence or core structure of experience (i.e., naked experience as separate from extraneous detail), Husserl proposed that the researcher must engage in a process of phenomenological reduction in which all beliefs, assumptions and preconceived notions regarding the phenomena to be studied are identified, made explicit, and then set aside or bracketed (Beck, 1994). Husserl’s argument was that phenomenology leads us back to the things themselves before we can apply our pre-understanding (Kearney, 1994).

Luft argued that Husserl's approach risks being superficial as it can only conclude with generalities (Luft, 2004).

Husserlian phenomenology is primarily interested in the nature of knowing, and focuses on the experience itself. The aim is to study experience as it occurred in consciousness, in an attempt to glimpse the phenomenon in its immediacy and as it is experienced, before the phenomenon has been overlaid with explanation as to causes or origins (Wilcke, 2002, p. 2). According to Husserl, phenomenological reduction is a process of defining the pure essence of psychological phenomena. Empirical subjectivity is suspended so that pure consciousness may be defined in its essential and absolute being (Wilcke, 2002, p. 1). This is accomplished by bracketing. In referring to the suspension of judgement with regard to the true nature of reality, Husserl used the term *epoche* (Greek 'cessation').

Husserlian phenomenology is built around the idea of reduction, a process that attempts to reach the core or essence of pure consciousness. Bracketing is a way to promote objectivity (Dowling, 2004), which clears the mind of previous experiences (Dowling, 2007). The researcher's preconceptions are set aside to ensure that assumptions do not shape data collection or impose on the phenomena (Crotty, 1996; Polit & Beck, 2008). Bracketing allows researchers to understand themselves and the participant as distinctive beings with unique experiences (Crotty, 1996). Parahoo argued that due to the fact that researchers might not be aware of the need to distance themselves, it might be impossible for them to totally suspend their presuppositions (Parahoo, 2006). Van Manen (1984) further warned that if one simply tries to ignore what one already knows, one's presuppositions may persistently creep into reflections. Instead, he suggests that researchers make their

beliefs explicit, and must tease out their bias and assumptions so that they do not just try to forget them. Rather, researchers should attempt to turn preconceived knowledge against itself so that its shallow or concealing character can be exposed (van Manen, 1984, p. 46).

Moran (2005) described Husserl as a phenomenologist and a transcendental philosopher. Transcendental phenomenology was the original form of phenomenological philosophy as conceptualised by Husserl. The basic premise is that experience must be transcended to discover reality (Moran, 2005). Kakkori states that reduction in transcendental phenomenology provides practitioners with pure consciousness, within which everything that exists is an object of pure consciousness (Kakkori, 2010, p. 21). Earlier phenomenological reflection had aimed to provide a foundation for scientific knowledge by reflecting on it, only possible by giving up the natural attitude. Husserl suggested that we should go back to the things themselves and transform our natural attitude by adopting a phenomenological approach (Husserl & Carr, 1970). Finlay pointed out that the phenomenological attitude involves an attempt to suspend presuppositions and view the world without any pre-understanding of it (Finlay, 2008). Van Manen (1990) noted that Husserl used the term 'natural' to indicate what was original, before the critical or theoretical reflection. Philosophy that believes it operates on a realistic level was bound to the natural attitude and cannot be critical in the transcendental sense. In the natural attitude, one was immersed in and lost from the experience (Dahlberg & Halling, 2001). This framing of the epistemological problem motivated the push into phenomenology, which is involved with becoming aware of the limits of natural attitude (Luft, 2004; Moustakas, 1994). In the phenomenological attitude,

individuals withhold judgement and construct a new way of looking at things. For Husserl, phenomenology was necessarily transcendental philosophy, entailing adherence to the relatedness of all experience.

3.8 Heidegger and the Hermeneutic Approach

Heidegger began his career as a student of Husserl, and while he acknowledged the value of Husserl's work, he moved away from his teacher's interpretation of the philosophy. The central problem for Husserl was the problem of constitution: how is the world as a phenomenon constituted in our consciousness? (Kakkori, 2010). Heidegger took the Husserlian problem one step further. Instead of asking how something is given in consciousness in order to be constituted, he asked: 'What is the mode of being in which the world constitutes itself?' (Heidegger, 1996). In rejecting Husserl's philosophy, Heidegger argued that self and consciousness could not be separated. Together, he argued, they constituted the historical formation of experience (Lavery, 2003). Heidegger's work has strongly influenced philosophy in the humanities, and within the discipline of philosophy itself it plays a crucial role in the development of existentialism, hermeneutics, deconstructionism and post-modernism.

Comparing views in hermeneutics, Van Kelst et al. (2013) suggest that phenomenology was descriptive when based on Husserl's approach and interpretive when based on Heidegger's. Researchers use hermeneutic phenomenology when they seek the meaning of the phenomenon in order to understand participants' experiences (Van Kelst et al., 2013). According to Flood, hermeneutic phenomenology focuses on describing the meaning of individuals, and how these meanings influence the choices they make, rather than seeking descriptions of the

real or perceived world (Flood, 2010). For Heidegger, Husserl's phenomenology was theoretical and abstract, and he challenged Husserl's construction of phenomenology as purely descriptive.

Husserlian phenomenology recommends that we withhold the natural attitude or suspend assumptions concerning knowledge about the phenomenon. Heidegger questioned the possibility of the acquisition of any knowledge other than interpretation, while he emphasised the world of people, relationships and language (Smith et al., 2009, p. 17). Heidegger considered the possibility of any description being without interpretation to be impossible, either in the way of its telling, its recording or its re-telling (Mackey, 2005). As a result, Heidegger introduced interpretation as both a concept of and method for phenomenological research (Heidegger, 1962, p. 62). Heidegger argued that we were already in the world, not as 'observing' but as 'being-inseparable from a world of being' (Maggs-Rapport & Wainwright, 2006). Heidegger (1962) thus argued that all understanding was interpretive and arose out of our being in the world.

Heidegger's perspective is *Dasein* or 'being', the term for subjectivity rather than pure conscience (van Manen, 2007). According to Heidegger, the concept of 'being' is central to phenomenology, and clarity comes by being in the world, not separate from it. Heidegger advocated a return to a practical 'being in the world', allowing the world to reveal itself. He maintained that 'being' was influenced by the present, past and future (Heidegger, 2006). This 'being' in the world dissolved the Cartesian dualism of person/world, subject/object and mind/body, because individuals exist in the world with things and with others: 'Man is in the world and only in the world does he know himself' (van Manen, 2007, p. 186).

In hermeneutical phenomenology, Heidegger viewed human beings as concerned with life and experiences as lived (Koch, 1996). For Heidegger, philosophical enquiry needed to be conducted by a process of retracing the history of philosophy. He suggested that humans represented their own world and their interpretation of it through words and language. Heidegger further asserted that it was not possible to separate oneself from one's preconceptions and pre-understandings completely (Converse, 2012). Rather, it was important to make these preconceptions clear, and to avoid imposing our own interpretations onto the text. Seen in this light, in this study the written text of interviews was used to understand the experiences of interviewees.

According to Heidegger (1962), and Gadamer (Gadamer, 1989), it was our preconceptions or understandings that channelled new ideas and guided interpretation. Benner also suggested that, by engaging in the interpretive process, the researcher sought to understand the world of concern as viewed by participants (Benner, 1994). These are then utilised to extract similarities and differences from participants' narratives: 'Understanding human concerns, meanings, experiential learning and practical everyday skilful components when they are functioning smoothly or are in breakdown is the goal, as opposed to explanation or prediction through casual law and formal theoretical propositions' (Benner, 1994, p. vx). Therefore, the researcher is required to make sense of data by engaging in an interpretative relationship with the transcript, to understand the participants' world. Hermeneutical phenomenology focused on collating details and various aspects within the experience, in order to create meaning and achieve a sense of understanding of the phenomenon (Laverly, 2003).

3.9 van Manen's Hermeneutic Phenomenology

Van Manen's approach to phenomenology is considered more action-sensitive than philosophical. Van Manen (1990, 1997) interpreted hermeneutic phenomenology in a comprehensive way, and allows it to encompass a wide range of practices. Typically, he focuses on phenomenological writing that can illuminate the silent parts of the story. He clarifies the distinction between phenomenology and hermeneutics, stating that phenomenology is pure description of lived experience, while hermeneutics is an interpretation of experience via some text or symbolic form (van Manen, 1997, p. 25). Van Manen (1990, p. 9) describes phenomenology as 'the world as we immediately experience it; pre-reflectively rather than as we conceptualise, categorise or reflect on it'. According to van Manen, the goal of hermeneutic phenomenological research is to develop a rich description of the area of study in a particular context; its emphasis focusing on the world lived by a person (van Manen, 1990, 1997). Van Manen (1990) posits that phenomenological research succeeds when meanings can be made recognisable.

3.9.1 Use of van Manen's hermeneutic phenomenology in this study

My desire to conduct this study was driven by the fact that I wanted to interpret the essence of the nurses' experiences of providing care to PLWHAs or those with related chronic illnesses in the community in Botswana. Van Manen (1997, cited in van Manen, 2007, p. 345) states that:

phenomenological understanding is distinctly existential, emotive, enactive, embodied, situational and no theoretic; a powerful phenomenological text thrives on a certain irrevocable tension between what is unique and what is

shared, between particular transcendent meaning and between reflective and pre-reflective spheres of life world.

Van Manen's phenomenological approach was used to guide this study's investigative process because it is interpretive, open to innovation and emphasises dialogue through self-reflection (van Manen, 1990). The philosophical underpinning of van Manen's phenomenology is consistent with my values and beliefs about the life world of the phenomena under examination. According to van Manen (1990), research using phenomenology seeks to uncover meaning in our experiences, with the aim of fulfilling our human nature. In hermeneutic phenomenology, researchers interpret human experience as though it were a text, with outcomes that include rich and deep accounts of the phenomenon (Hein & Austin, 2001). I explored the phenomena as they presented to the consciousness of the person. According to van Manen (1997), the central structure of an experience is in its intention, or how the individual experiences it in their lived world.

Van Manen proposes that researchers must first engage themselves thoroughly in the phenomenon to be investigated, then reflect on the essential elements or themes of the interview experiences. Such themes are not objects or generalisations, but actual experiences as lived (van Manen, 1990). Therefore, in this study, the aim was to describe and interpret the meaning of nurses' everyday experiences as they deliver care to PLWHAs in the community, and to distil themes from their narratives. According to Colaizzi, the purpose of a researcher reflecting on his or her underlying assumptions is to become aware of their own biases, in order to engage with the research process without having any preconceived ideas about the results of the study (Colaizzi, 1978). Lavery (2003) points out that in a

hermeneutic approach, the researcher must engage in a process of self-reflection. Bias and assumptions are embedded, and are essential to the interpretation of experiences (Laverty, 2003). As an interpretive phenomenological researcher one cannot separate or bracket what is already known (van Manen, 1990). For me, this meant acknowledging my previous experience working with people in this situation, and the experiences gained from seeing my own cousin cared for in the community. Further, van Manen (1997) suggests that it is necessary for the researcher to become immersed in the phenomenon in order to develop a clear understanding of the nature of lived experiences, as well as to ensure that she/he does not take anything for granted. In this regard, I spent time working with nurses who provide care to chronically ill people living in the community in Botswana. Botswana is my place of origin, so I possessed an intimate knowledge of the issues faced by patients and nurses in this country.

Interpretive phenomenology's primary concern is the understanding of individuals' lived experiences, with the goal of establishing the context in which the phenomena manifest themselves (Rapport & Wainwright, 2006; Valle et al., 1989). Further, van Manen (1990) maintains that researching lived experiences should result in an expanded understanding that helps the researcher to act tactfully and thoughtfully in future interactions with participants. The goal of hermeneutic enquiry is to identify the participants' meanings and thus offer an approach to researching the complex world of human experiences. It accommodates non-empirical data such as values, beliefs and feelings (Mackey, 2005). Additionally, the hermeneutic approach does not define a systematic formula to follow for data collection and analysis. However, van Manen (1990, pp. 30–31) outline six broad guidelines for a

phenomenological study (which are not intended to be prescriptive). I chose to adhere to these guidelines:

1. Turning to a phenomenon that interests us and commits us to the world.
2. Investigating experience as we live it rather than as we conceptualise it.
3. Reflecting on the essential themes that characterise the phenomenon.
4. Describing the phenomenon through writing and rewriting.
5. Maintaining a strongly-oriented pedagogical relationship to the phenomenon.
6. Balancing the research context by considering the parts of whole.

3.9.2 Applying van Manen's guidelines to this study

3.9.2.1 Turning to a phenomenon that interests us and commits us to the world

For this study, I chose to interview experienced palliative CHBC nurses who work in clinics, and those involved in the delivery of community-based palliative care. These nurses were interviewed because they are directly involved with patient care. I hoped that the nurses would supply practical information that would provide insight about community palliative care in Botswana and its challenges. Awareness of the challenges experienced by nurses on their everyday work life enhanced my ability to capture key issues in community palliative care in Botswana.

3.9.2.2 Investigating experience as we live it, rather than as we conceptualise it

The data collection method used to investigate the lived experience of nurses delivering community palliative care in Botswana was that of tape recorded and transcribed semi-structured interviews. According to van Manen (1990), personal experience is the starting point in phenomenology. Thus, I attempted to describe my experience as much as possible in experiential terms, focusing on a particular event. I also attempted to give a direct description of my experience as it was, without offering any casual explanation or interpretative generalisation of my experience. Participants were asked to describe their experiences in their own words, and their narratives added depth to the understanding of palliative care delivery by nurses.

3.9.2.3 Reflecting on the essential themes that characterise the phenomenon

Van Manen (1990) stated that to do human science research is to be involved. Reflecting on lived experiences morphs into reflectively analysing the structural or thematic aspects of that experience (p. 78). Reflective notes were taken during the interview, which assisted in the analysis. After each interview, the recording was transcribed verbatim and analysed by identifying common themes and assigning meanings. All three of van Manen's process approaches were employed to reflect on the themes (holistic, selective or highlighting approach and the detailed or line-by-line approach) (van Manen, 2002). Interviews continued until themes were revealed and richly described. I recognised, however, that no interpretation would ever be complete, no explication of meaning ever final and no insight beyond challenge (van Manen, 2002, p. 237).

3.9.2.4 Describing the phenomenon through writing

According to van Manen (1990, 1997), writing describes the richness of the phenomena within the lived experiences and allows the writer to put form and shape to his/her thoughts. As Giorgi (1997) noted, description gives an expression to the object as it appears, and communicates objects of consciousness as they are presented. Writing is both the progress and product of phenomenological inquiry, and I wrote to fully enquire about the phenomena under study (Giorgi, 1997). The art of writing and rewriting brought meaning to the surface. Writing separates us from the experiences, and through this separation we are able to reflect on everyday experiences. Phenomenology is a process of interpretation through reflection, and 'to write is to measure our thoughtfulness' (van Manen, 1990, p. 127). Through writing and rewriting there is on-going revision and refining of thought. Ideas formed during data collection and transcription processes became clear. By questioning and reflecting on the emerging themes, understanding of the nurses' lived experiences developed.

3.9.2.5 Maintaining a strongly-oriented pedagogical relationship to the phenomenon

The focus of writing and research must be guided continually. Van Manen (1990, p. 135) suggests that modern educational theory suffers from three main problems:

- Confusing pedagogical theories with other discipline-based forms of discourse.
- Tending to abstraction, and thus losing touch with the life world of the living.

- Failing to see the general erosion of pedagogical meaning from the life world.

Van Manen (1990) suggests that the writing and evaluative criteria of any phenomenological human science text needs to be oriented, strong, rich and deep. For a text to be rich the meaning of the lived sense of the phenomenon are exhausted in their immediate experience. My strength in investigating nurses' experiences of community palliative care in Botswana comes from a personal perspective of being a community nurse in Botswana, and observing a family member suffer without adequate support. I shared circumstances with the participants but required frequent contact with colleagues to reflect on the research process. This helped to maintain concentration on the task at hand.

3.9.2.6 Balancing the research context by considering the parts of whole

According to van Manen (1990, p. 162), research is a balance of explicit statements on the methodological process and openness that allows for choosing directions and exploring techniques and sources that are not always obvious at the onset of the study. In this context, I considered the effects that the research might have on nurses delivering palliative care in the community. Reading the interview transcripts, considering my understanding, scrutinising the parts again and rewriting is a process that continued throughout the data analysis process.

3.10 Role of the Researcher in Hermeneutic Research

Hermeneutic phenomenology is both the theory and practice of interpretation of the meaning of texts (Rennie, 1999). It is a philosophy that aims to achieve understanding through interpretation, and adopts a process that clarifies the

phenomenon of interest in its context, as opposed to presenting its essential structure (Hein & Austin, 2001). Hermeneutics as a research method is based on the belief that lived experiences are essentially an interpretative process (Cohen & Omery, 1994). Hermeneutic phenomenology investigates the interpretive structures of experiences of individuals or texts. The interpretive focus is from the outside from the perspective of the objective researcher or from the inside with a focus on interaction between the interpreter and text.

Hermeneutic phenomenology investigates and describes a phenomenon as experienced in life through phenomenological reflection and writing (Smith et al., 2009), thus developing a description of the phenomenon that leads to an understanding of the meaning of the experience (Flood, 2010; Rennie, 1999). Hermeneutic phenomenology does not seek to set aside biases and assumptions, but sees them as embedded and essential to the interpretive process (Polkinghorne, 1983; van Manen, 1997). Hermeneutic researchers reject the concept of setting aside the researcher's experience and understanding of the phenomenon (Finlay, 2008). Rather, they believe the researcher's understanding and awareness assists in examining and questioning pre-existing beliefs in relation to new information. Van Manen warns that if researchers attempt to ignore what they already know, their presuppositions may later emerge in their reflection (van Manen, 1984). Rather than bracketing prior knowledge, he suggests that researchers make explicit their beliefs, biases and assumptions so that they can turn this knowledge against itself. In this way, the shallow or concealing character of these preconceptions can be exposed (p.46). This idea is supported by Mills, who suggests that each person has his/her own subjective reality, making experiences unique to individuals (Mills, 1994).

3.11 Ethical Considerations and Local Approvals

Ethical approval to conduct the study was sought from the James Cook University Human Research Ethics Committee. Approval was granted in 2011 (approval number: H4221). After obtaining approval from the university and the Botswana MoH, I wrote to the DHMT coordinators of each participating district, explaining the purpose of the proposed study and requesting support in recruiting participants. District managers were contacted by telephone to confirm that I would be arriving in their district a day before data collection. The schedule of visits was attached to the letter. Potential participants were notified a day before my arrival. The participants and the managers identified the venue, and the timing of interviews was dependent upon nurses' clinical schedules. One participant was interviewed at her home because she was busy during work hours and had to go home because her child was alone.

3.11.1 Measures taken to avoid management coercion of the research interviewees

Participation in the study was voluntary and only the researcher and the clinic managers were aware of who volunteered to participate in the study. Sensitivity towards the power imbalance between the nurses and their managers was avoided by asking the participants to nominate a place where they would like to have the interview conducted. This avoided the possibility of managers being able to influence the participants' responses, as would have happened if the interview place was identified by the managers..

3.11.2 Ensuring participant confidence and safety throughout the interview process

Once introduced to the participants, I provided them with an explanatory statement and written consent form to sign and return if they agreed to participate. To create rapport and an honest and open relationship, I spent some time talking about the research and the purpose of the study. I explained the interview process as well as my role as researcher. The interaction was conducted in a manner aimed to invite participants to be honest about their experiences in a non-coercive manner. Lavery argued that for the interview process to allow the participants freedom of expression, an environment of safety and trust must prevail at the onset of the research (Lavery, 2003). Leedy, (1997) observed that when dealing with research ethics, it is necessary to remember that the principles of honesty and openness of intent by the researcher are fundamental (p. 116). These must be respected, to guarantee individual privacy and informed willingness to participate voluntarily in the research.

3.11.3 Right to informed consent

The process of consent is designed to protect the autonomy of patients and their self-determination (Cole, 2012). According to Corbin and Morse, informed consent guidelines for participants should not be based on promises or guarantees of benefits that might encourage or influence participation (Corbin & Morse, 2003). Christopher et al., (2007) stated that although written forms of consent are not the only means of communicating information to and receiving consent from potential participants, they are typically more complete than verbal disclosures, and are relied upon by institutional review boards to ensure that all necessary information is

conveyed. (p. 227) For this study, I obtained written consent after all participants were given sufficient information about the interview purpose and procedures of the study. The information sheet included my expectations of the participants during interviews. The consent form was documented according to the James Cook University guidelines for research subject protection. It is the researcher's responsibility to ensure that the environment is suitable for the participants. Interviews were held at a place chosen by the participant.

3.11.4 Right to beneficence

In this study, I specified the importance of participants having the right to express their experiences, to be heard and to have freedom of choice when responding to questions that might be uncomfortable to answer. Beneficence in qualitative research is an ethical principle that encourages doing good to others and preventing harm from happening to them (Kinsinger, 2009; Polit & Beck, 2009). I gave managers strict guidelines that participation was strictly voluntary. Participants were clearly informed about the study and reminded of their rights. Thus, potential participants were invited to participate voluntarily, and were told that they were free to contact the researcher at any time after the interviews should they need clarification or to ask anything further about the study.

3.11.5 Right to autonomy and self-determination

I explained the focus of the study to the participants in order for them to understand its significance. This explanation allowed participants the opportunity to decide whether or not they wanted to proceed with the interviews. Respect for autonomy is one of the guiding ethical principles in research involving humans, and requires that individuals be granted appropriate autonomy (Munung et al., 2012).

This was observed by providing information from which a decision to participate could be made, and obtaining written informed consent from all participants' before beginning interviews. I provided a written explanatory statement about the study to potential participants, and a verbal explanation or clarification to each potential participant prior to seeking written consent. I re-negotiated consent prior to the interviews. This follows the approach of King and Horrocks, who noted that in qualitative research consent should not only be obtained at the time of consent, but also at the start of the first and subsequent interviews (King & Horrocks, 2010).

The principle of self-determination means that prospective participants have the right to decide voluntarily whether to participate in a study without risking penalty or prejudicial treatment (Polit & Beck, 2008, p. 171). Participants in this study were informed that participation was voluntary and that they could choose to withdraw at any time without penalty. It was emphasised that withdrawal would not affect their position or relationships at work. Participants chose to become involved under no duress, understood their rights and were subjected to no external influence to participate. Since a person's right to self-determination includes freedom from coercion of any type, participants were not promised any rewards or incentives for participating in the study.

3.11.6 Right to privacy and confidentiality

I had a responsibility to ensure that the rights of participants were preserved. I made sure that no participant identities were revealed or shared without permission. Potential participants were assured that their anonymity would be protected at all times by the use of pseudonyms in all data transcriptions, resulting chapters and publications.

All information gathered was treated with the strictest confidentiality. Participants were informed that information obtained in the course of data collection would be kept confidential, and that no names would be linked to the data. During the interviews, all documents including those bearing real names were locked securely in my suitcase prior to transcription. Pseudonyms and codes were used to de-identify data during the transcription process, and information related to these codes was accessible only to me.

3.11.7 Welfare of participants

Participants were informed that they were not expected to experience any discomfort as a result of their participation in the study. However, should a participant become distressed during the interview, she/he would be referred to a local nurse who was available for support. Prior to data collection, arrangements were made for the provision of support in the event of participants becoming distressed.

3.11.8 Reflexivity

Reflexivity is a process of continual internal dialogue and self-evaluation of a researcher's position, and acknowledgement and recognition that this position may affect the research process and outcomes (Berger, 2015). It is a process in which researchers engage in analysis of their role (Finlay, 2002). I made a conscious attempt to continuously re-evaluate my involvement and examine my assumptions and preconceptions of the phenomena under study. Personal responses and thoughts about the research and research participants were taken into account, and I considered how those affected my research decisions when selecting wording or interviewing participants.

3.12 Data Collection

3.12.1 Selection of participants

A purposive sample of 13 community nurses drawn from 12 districts of Botswana resulted in 13 interviews (see Table 1 for information on the participants). Purposive sampling is a form of non-probability sampling in which decisions concerning individuals to be included in the sample are taken by the researcher. These decisions were based upon a variety of criteria, which may include specialist knowledge of the research issue, or capacity and willingness to participate in the research (Oliver & Jupp, 2006). Denzin and Lincoln (2000) and Patton (2002) suggested that purposive sampling is the most important kind of non-probability sampling when identifying participants' ability to provide rich data (Denzin & Lincoln, 2000; Patton, 2002). CHBC nurses were invited to participate in this study because of their experience caring for PLWHAs requiring palliative care in the community in Botswana. The aim was to recruit participants who had lived the experience of interest. In this way, understanding the experiences documented by those who have lived them, and allowing them to speak, was thought to shed light on the phenomenon (Guimond-Plourde, 2009). Gathering examples of experiences was an activity 'woven into the explorative questioning of a particular phenomenon of interest' (van Manen, 2014, p. 281).

The geographical location, size of districts and density of population were important selection criteria. Further, districts were identified from a representative range of districts based on the size of their operations. The rationale for covering a wide area was that there could be different responses from participants located in these areas, indicating different experiences. Creswell recommended up to 10

participants for phenomenological studies (Creswell, 1998). However, Sandelowski argued that researchers may continue to engage in interviews with participants until they believe there is no new information being generated (Sandelowski, 1986). The latter was the case in this study, with data collection ceasing after 13 interviews when the same information was recurring.

Eleven of the participants were females and two were males (see Table 1). This balance reflected the fact that nursing is a female-dominated profession in Botswana. The participants' years of employment in nursing ranged from six to 30 years. This participation range was an advantage, as it produced a wide variety of experiences. In terms of education completed, most nurses had acquired a Diploma in General Nursing, while one nurse had a Bachelor of Nursing degree.

Table 1

Participants' Profiles

Pseudonym	Age	Gender	Level of education	Length of nursing experience (years)	Length of work as CHBC nurse (years)	Trained in palliative care
Kago	40	F	Diploma in General Nursing & Diploma in Midwifery	18	18	N
Shirley	29	F	Diploma in General Nursing	6	6	N
Lebang	34	F	Diploma in General Nursing	12	12	N
Tshepo	41	M	Diploma in General Nursing	11	11	N
Bonno	45	F	Diploma in General Nursing	25	25	Y
Colleen	40	F	Diploma in General Nursing	16	4	N
Tshepang	50	F	Diploma in General Nursing & Diploma in Midwifery	24	3	Y
Kate	43	F	Diploma in General Nursing & Diploma in Midwifery	18	3	Y
Pretty	57	F	Diploma in General Nursing & Diploma in Health Administration	36	3	Y
Taboka	25	F	Bachelor of Nursing Science	3	3	N
Josefa	45	M	Diploma in General Nursing	20	10	Y
Neo	54	F	Diploma in General Nursing & Diploma in Midwifery	30	12	Y

3.12.2 Interview process

To understand the meanings attributed to particular experiences in the real world, qualitative researchers employ data collection methods conducive to collecting data through verbal interaction with the participant in the form of an interview. A semi-structured interview approach was adopted to guide the interview process. According to Morse and Field (1995) and Speziale and Carpenter (2003), open-ended questions allow participants the maximum freedom to respond and provide a detailed description of their lived experiences (Morse & Field, 1995; Speziale & Carpenter, 2003). According to Smith and Osborn (Smith & Osborn, 2007, p. 63), it is sensible to concentrate on putting participants at ease at the beginning of the interview, to enable them to feel comfortable talking to the researcher before any substantive areas of the schedule are introduced. The use of semi-structured interview was deemed particularly useful in order to gain a detailed understanding of participants' beliefs and their perceptions of the phenomenon (Smith & Osborn, 2007).

Participants were initially asked the open-ended question: 'What is it like for you to deliver community palliative CHBC to PLWHAs and those with associated chronic illnesses in Botswana?' During the interview process the interviews lasted between 40 and 65 minutes. A number of interviews were interrupted due to work commitments, especially those located at the clinic or district office. In these cases, interviews had to be halted for up to 20 minutes. However, Smith and Osborn (2007) point out that it is sensible to avoid interruptions wherever possible.

Qualitative interviewing is an interchange of views between two people conversing about a topic of mutual interest, with the researcher attempting to

understand the world from the participant's point of view, while helping them describe their experiences (Groenewald, 2004). In this study, interviews were used to explore and collect stories of nurses' experiences, to uncover a rich understanding of the area of study, and to create an understanding between the researcher and the participants about the meaning of the experience (Ajjawi & Higgs, 2007; King & Horrocks, 2010).

Interviews were generally conducted at the workplace, either at the clinic or at the District Health Team offices. One was conducted at the nurse's home, as she had to care for her baby. Interviews were tape recorded with participants' permission, although recording an interview can limit participants' openness, resulting in them withholding information that would enrich the data (King & Horrocks, 2010). Smith and Osborn (2007) suggested that it is difficult to record an interview without tape recording it, as some information is not captured (Smith & Osborn, 2007). After a detailed and clear explanation about the need for the tape recorder, participants were asked for permission to use it during the interview. They were assured of confidentiality and that tapes would be kept in a safe place. Unfortunately, many participants were uncomfortable with tape recording, as they thought the information would be passed on to the MoH. Some participants were still not forthcoming with information while the tape was recording, but did open up when the tape was turned off. I took extensive notes to overcome the limitations of participants' reluctance to be tape recorded. With the participants' permission, these notes were used as a backup strategy to capture key phrases and major points made during the interview while the tape recorder was turned off.

In Botswana, all nurses speak fluent English, but in order to clarify their views, participants were informed they were free to use their local language (Setswana). As I am a fluent speaker of both English and Setswana, it was possible for the participants to easily express themselves and tell their stories accurately. Each interview was assigned a code and was recorded on separate tapes. Tapes were processed after every interview: notes made immediately and keywords noted. Field notes proved useful in capturing information that might have been missed. Additionally, these notes were used later in the process of data analysis and interpretation.

3.12.3 Data analysis

Data analysis is the process of bringing structure and meaning to the data collected. In qualitative research, data analysis begins at the beginning of data collection (David & Sutton, 2004). According to Polit and Beck (2004), analysis involves extracting significant statements that allow identification of recurring themes (Polit & Beck, 2004). Therefore, the goal of phenomenological analysis is to arrive at some structure by which the essence of the phenomena under investigation can be described (Giorgi, 1997). The aim of data analysis is to transform lived experiences into a textual expression of its essence. This was done in such a way that the effect of text was ‘a reflexive re-living and a reflective appropriation of something meaningful’ (van Manen, 1990, p. 36). Van Manen (1990), stated that ‘grasping and formulating a thematic understanding is not a rule-bound process but a free act of “seeing” meaning’ (p. 79).

3.13 Themes in van Manen's Hermeneutic Analysis

Isolating thematic statements from the data collected involved asking what each sentence revealed about the phenomenon: the holistic approach sought to uncover an overall meaning of the text, the selective approach focused on outstanding phrases and sentences of the text and the line-by-line approach involved close examination of the text sentence by sentence. What were called 'themes' were not necessarily 'the same thing' said again and again, but rather an understanding that we have seen something that matters significantly, something that we wish to point the reader towards (Smythe et al., 2008,p. 1392). Therefore, I was required to make sense of the data by engaging in an interpretive relationship with the transcript, in order to understand the participants' world.

3.13.1 Isolating thematic statements

To identify what the sentence or group of sentences reveal, I engaged in thorough reading and re-reading of the transcripts, and identified key words and concepts that appeared in particular sentences. These were then grouped together.

3.13.2 Selective or highlighting approach

The second stage of analysis was asking which statements were most revealing about the experience of nurses delivering community palliative care. These statements were then highlighted and tabulated.

3.13.3 The holistic reading approach

This method was used throughout the analysis because it involved looking at the text as a whole and asking which phrase captured its fundamental meaning. The detailed reading approach was used to identify what each sentence revealed about the

phenomenon. For example, according to Spinoza, interpreting a text such as the Bible requires the reader to understand the verses in a chapter, and then to consider how it fits into the meaning of the scripture (Spinoza, 2005).

3.13.4 The hermeneutic circle in data analysis

Heidegger viewed the hermeneutic process as creating circles of self-reference in the understanding of the world (Spinoza, 2005). However, Gadamer reconceptualised the hermeneutic circle as a process by which new understanding of a whole reality is developed by means of exploring the detail of existence (Gadamer, 1975). Grondin described Gadamer's concept of the circle 'as the constant process that consists of the revision of the anticipation of understanding in the light of a better understanding of the whole' (Grondin, 2002) (p. 47). Heidegger later proposed the philosophical hermeneutic process, in which human existence could be understood and interpreted using the hermeneutic circle.

The hermeneutic circle and other concepts of Heidegger's phenomenology informed van Manen's (1990) method of analysis, and were used for interpretation and analysis in this research. Hermeneutic phenomenology employs the concept of the hermeneutic circle in data analysis. The creation of the hermeneutic circle involves the process of coming to understand the being of something by moving iteratively between the whole and parts and back again (Finlay, 2011, p. 115). Bontekoe (1996) suggested that in hermeneutics, our grasping of new understandings depends on what was already understood in the past. The history of human understanding is presented by the hermeneutic circle, in which continuous flow of information prevents it from becoming a downward spiral (Bontekoe, 1996, p. 2).

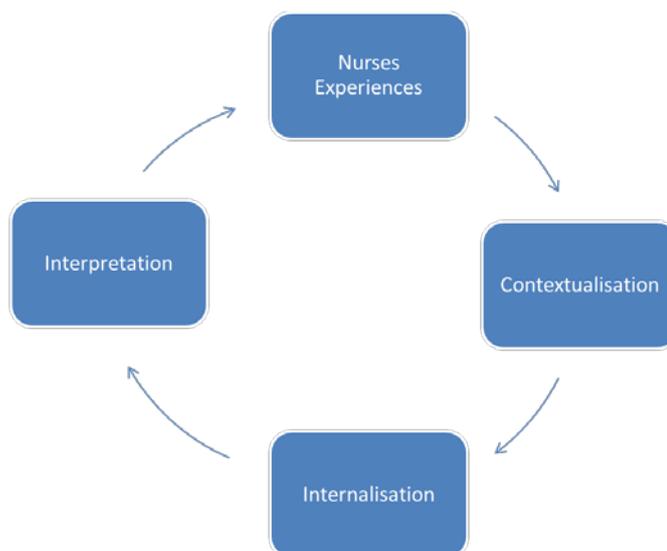


Figure 5. The hermeneutic circle, adapted for the current research (Bontekoe, 1996, p. 2).

In the process of textual interpretation, the hermeneutic circle describes the relationship between parts and the whole of the phenomenon as being always intertwined (Bontekoe, 1996). Draper (1996) describes the process of creating the hermeneutic circle as giving an adequate account of the entire text by building up the account through identification and interpretation of meaning. The researcher moves in and out of the imaginary circle, connecting with other parts, then the whole, and then the parts once more, each time increasing understanding (Draper, 1996). According to van Manen (1997), the hermeneutic circle refers to the fact that the way one understands the phenomenon as a whole is determined by reference to the individual parts, and one's understanding of each individual part is determined by reference to the whole. The interpretation is found within the context and is recognised, and this context is continually changing throughout analysis. Data interpretation is thus an on-going process moving backwards and forwards, in order to understand the phenomenon as a whole. According to van Manen (1997), the

development of the hermeneutic circle involves the researcher reflecting on the inquiry process by reading and re-reading the text.

3.14 Data Analysis Mechanics

The data analysis process was reflective as I fully immersed myself in the data through listening to the audio recordings, transcribing the interviews and re-reading the transcripts. I transcribed all audio-tapes. As Balls observed, for researchers to be familiar and immerse themselves in the data, they need to transcribe the interviews themselves (Balls, 2008). As some of the participants used both English and Setswana, each transcript took between four and five hours to complete. When I listened to the tapes it became clear that in some sections I had to repeat a question, and also clarify it in the local language.

The analytical process began by looking at features of each case to ensure that the personal phenomenological aspects of participants' experience and meaning were preserved. The initial stages of data analysis involved reading transcripts and listening to the tapes, and summarising and paraphrasing the raw data. I summarised the transcripts and noted key points made by participants in response to the questions. The transcribed interviews were read several times to gain an overall general understanding of each participant's worldview. This is what van Manen (1990) calls the line-by-line reading of transcripts. At this stage, initial impressions were noted on separate pages and the accounts were assessed in context with my experience of the interviews. Anecdotes were then drawn from the interviews to assist with accessing the experience. Extraneous and redundant material was removed in order to transform the transcript stories into themes (van Manen, 2014).

Manual codes were developed and texts were identified and organised into hard copy folders. The use of these templates provided a clear trail of evidence for credibility. Templates were developed based on the research questions. At this stage, analysis of the texts was guided but not confined by preliminary codes. During the coding of transcripts, codes were assigned to segments of data that described the theme observed in the text. I met with the advisory team and folders with raw data were created.

The writing of text became a key component of the analysis, from which the phenomenon was illuminated. This process required continual writing and rewriting to allow the phenomenon to speak for itself (van Manen, 1990). The supervisory team reviewed drafts of the texts on numerous occasions, to ensure that the phenomenological description resonated with the lived experience.

3.15 Conclusion

This chapter has discussed the qualitative design, informed by the hermeneutic approach of van Manen (1990). Phenomenology was explained and described through the works of van Manen and Heidegger. Van Manen's (1990) six-step method of phenomenological research was outlined, and the concept of the hermeneutic circle in data analysis was explained. Ethical considerations were outlined and discussed as relevant to this study. The following chapter provides a detailed discussion of the findings.

Chapter 4: Study Findings

4.1 Introduction

The current study was undertaken to explore the experiences of nurses who provide home-based palliative care to PLWHAs and related chronic illnesses in Botswana. Qualitative data analysis of the interviews resulted in the emergence of four themes. The study found that nurses are:

- Working in chaos. They struggle to deal with the consequences of the governmental restructure on the health system.
- Struggling for advocacy. They experience difficulties advocating for safe and effective patient care, including effective pain relief.
- Dealing with HIV/AIDS stigma and discrimination. They are challenged by the need to deal with the stigmatisation of the illness, both in the community and among HIV-positive nursing health professionals.
- Struggling to support volunteers. They find it difficult to come to terms with the redistribution of responsibilities from nurses to volunteers.

Table 2

Themes and Sub-themes Identified by the Study

Themes	Sub-themes
Nurses working in chaos	Lack of engagement with the change process. Poor coordination of services. Out-of-context management. Lack of enjoyment.
Nurses struggling for advocacy	Perceived lack of power. Perceived lack of knowledge. Perceived lack of resources. Perceived lack of continuity of care.
Nurses dealing with HIV/AIDS stigma and discrimination	Community's negative attitudes. Community's shame and secrecy. Nurses' fear of ostracism. Role of ARVs in reducing stigma.
Nurses committed to support volunteers	Involving volunteers in the team. Accepting the limitations of volunteers. Supporting volunteers. Advocating for volunteers.

4.2 Theme 1: Nurses Working in Chaos

This section provides an overview of the first theme and sub-themes derived from the categorisation of participant responses. Results indicated that CHB nurses managing the palliative care of PLWHAs and related chronic conditions in the community were challenged by a recent governmental restructure of the health system. Participants felt there were too few nurses experienced in community work to conduct care in the community for people in need, including those who have HIV/AIDS-related illnesses, and the restructure contributed to an acute shortage of the resources required to provide effective care.

The findings revealed that the nurses were working in chaos. It was exceedingly stressful for them when everything around them was chaotic and it

seemed they no longer had control over the delivery of care. For example, they had no power to regulate what was happening within the work environment, had had limited communication about the relocation process, had to deal with issues related to poor coordination of services and were challenged by a management system that was out-of-context. All of these issues resulted in nurses experiencing a lack of enjoyment at work. Four sub-themes emerged that highlighted these challenges.

4.2.1 Sub-theme 1: Lack of engagement with the change process

Nurses' engagement in any restructuring of the delivery of community care is important for the success of the restructure, as nurses are responsible for the majority of community nursing care. It was apparent that the MoH had adopted a 'traditional' consultative culture during the restructure, which resulted in the MoH and MLG meeting with selected stakeholders and management within the bureaucratic system, but not with the CHBC nurses responsible for the delivery of care in the community. As two nurses stated: 'We were not involved in the discussions but I feel that we should have been represented because we know a lot about patients and we are the ones taking care of these patients' (Bonno) and: 'They did not tell us as nurses we just saw it happening, but we nurses we work under these situations they must ask us what is that can be done to improve the care of home-based care patients' (Neo).

The nurse managers' lack of communication about the change process left nurses in the dark about the proposed changes. This was viewed by participants as managers making unnecessary and uninformed change. Participants believed that if effective dialogue and discussions had occurred between them and their line managers, the outcomes would have been more positive.

Nothing to discuss, the problem is the relocation of services... I do not know what these people in high offices think of patients and us as nurses, we are the ones who are mostly affected by these changes. Here only the coordinators and the matrons at the DHT attended the meetings but we were never told until they started implementing. That was when we were told that there were some changes... it is hard. (Kago)

Lack of communication left nurses uninformed and anxious about the change process. Further, participants reported being suspicious that managers who cooperated with Ministry management were rewarded for their actions:

There seemed to be a lot of promotions for the management from the Ministry headquarters to the level of matrons. If people can stop wanting to have high positions and creating unnecessary changes there would be no problems. Because home care and primary healthcare were doing fine before this confusion. (Neo)

Participants also commented on how the promotion of managers was viewed suspiciously among nurses:

Because clinic nurses were not part of the discussion we did not see or understand the reason behind the relocation. I think this is all about creating positions for the high officers, I do not think there was a need for the change. (Shirley)

4.2.2 Sub-theme 2: Poor coordination of services

One problem that affected the delivery of home-based care after the reorganisation was inefficiency in the coordination of services between service

groups. According to the nurses' narratives, the relocation of PHC to the MoH was inappropriate. Participants explained that the coordination of community programmes by the MoH did not achieve its expected outcomes at the community level:

The Ministry of Health is supposed to be for national coordination, not for community or grassroots management. Now what we observe is that central government has different views and opinions about delivery of care at community level... I don't think they are aware that home-based care is different from hospital care. (Mmapula)

Participants described how they believed the MoH had assumed too much power over the DHMTs. Their contention was that the relocation has created an unintentional and unnecessary bureaucratic hierarchy, which has resulted in poor coordination of programmes:

Before relocation it was easy because everything was accessed locally. The coordination was done at district level at the council with people who had a clear understanding of community home-based care. For example, even the counsellor, you were able to pick up the phone and ask for transport by just saying we have patients who need transport to the clinic... it was easy because it was something they could see and relate with. (Shirley)

There was disruption and lack of coordination in the multidisciplinary teams that had operated successfully in the previous structure. Before, nurses had understood the roles of each group of team players, such as social workers, environmental health officers and CHB care coordinators. As Kate stated: 'When we

were at local government we knew what the other workers such as social workers, environmental health and coordinators were doing’.

Participants felt that services were now delivered in a disjointed fashion, with little consideration for the welfare of home-care based patients: ‘When we were under local government we were working easy with Social & Community Development services and everything was easily coordinated, from the DHT resulting in comprehensive delivery of care to home-based patients’ (Lebang).

Additionally, participants described how they began to feel professional dissatisfaction and uncertainty as they were not clear how to continue to provide effective care for patients at home: ‘The structure has changed, now all the clinics fall under the Ministry of Health... this has caused a lot of confusion and disruption in provide quality home-based care’ (Neo).

4.2.3 Sub-theme 3: Out-of-context management

The relocation moved existing clinic managers to the hospitals, while transferring hospital managers with no experience into community work, and the DHMTs were rotated on a promotional basis. In some cases, responsibility for a larger and more diverse range of health promotion and prevention services, as opposed to managing only hospital-based services, created problems for the DHMT’s new managers. Managers, who needed a good understanding of the context in order to plan and manage change, were failing to progress the community care agenda: ‘There are also a lot of new people in management positions who have no idea about community work... The relocation has caused problems for most primary healthcare services’ (Taboka).

This failure of leadership was generally attributed to new managers' capabilities and lack of preparedness for their new roles:

It is hard because we are struggling with new staff, especially the managers at DHMT, who do not have an understanding of how clinics work. There is no transport to do home visits. I feel patients are suffering without adequate care. (Lebang)

Participants reported encountering inequality in the allocation of nurses, and inappropriate use of staff within the system. Often, managers inexperienced in community work were more focused on curative care in hospitals and not on PHC services, resulting in an uneven and seemingly biased distribution of staff.

It seems more nurses are placed in hospitals, unlike before, nurses used to choose if they wanted to work for the clinics or hospital services. The other problem is that the managers, because they have never worked in the councils, I have a feeling that they think community work is easy. (Colleen)

Some participants attributed their lack of support to this lack of managerial experience and knowledge of community-based structures:

Management is not well conversant with these problems, so much that if it is a management issue they are the ones who are supposed to advocate but sometimes when these programmes are introduced they just target at us who are practicing, but those in management are not catered for, there is a need for them to know what you are talking about. Because when we are from workshops we give the report but at times they do not support us. So DHMT

and the hospital superintendent they are not doing justice to us because they are the ones who are supposed to support us. (Tshepo)

The redeployment of nurses was also a problematic issue. Participants described how the quality of home-based care was compromised due to the influx into the clinics of nurses inexperienced in community work, while experienced nurses were being transferred out:

You know the merging of services between local government and central government has brought us problems. There are a lot of nurses who have never worked in the council and some are even bosses, its problems... they have no idea in community care. (Tshepo)

Another participant said that ‘Nurses experienced in PHC have been replaced by nurses from the hospital who have no experience’ (Kago).

The transfer of experienced nurses out of the system impeded the creation and maintenance of critical nurse/client relationships. The lack of success in the delivery of effective palliative care was partially attributed to this constant rotation and transfer without negotiation.

To deliver this home-based care is very stressful in the sense that for me as a nurse I am stressed by dealing with these patients with chronic illnesses when they present with different conditions; it is difficult also, moving from one clinic to another does not give us time to know the patient. (Lebang)

Managing and dealing with change was made difficult for CHBC nurses through unending changes in their roles and responsibilities:

We are all new, we have just arrived and there was no-one to orientate us to home-based care patients. The rotation of nurses really destabilises the whole progress because when we get familiar to the clinic we get moved to another place (Lebang).

Participants emphasised that participation in communities over time was a fundamental part of creating good caring outcomes: 'Although we have knowledge of the patient's condition and their family setting we were not consulted when it came to transfers' (Kago). And: 'The frequent movement from one clinic to another cause a lot stress on the nurses. We have to learn the community and also it takes time for the family to get used to the nurse' (Bonno).

Participants also resented the fact that management was not adhering to official policy when initiating nurses' transfers: 'Accordingly we should be rotating among clinics every two years, that's what we were told but now that is not happening... at times we are transferred without any warning or negotiations' (Taboka).

This chaotic approach to transferring nursing staff extended into internal nurse transfers between clinics within a district. Participants were of the opinion that if they were left in one clinic for a reasonable length of time they would cope better, and less disruption would be experienced by their clients:

The rate of transfers is very high every year in a period of 12 months; people are being moved from one clinic to another. We end up with all new people, which takes time to orientate them. First April there was another staff rotation, all focal persons were taken to hospital. (Shirley)

Structural changes caused by the reorganisation involved removing Family Welfare Educators (FWEs) from home-based care duties. Participants suggested that the loss of assistance by FWEs contributed to the chaotic situation: ‘Family Welfare Educators used to do regular home visits and assess the patient’s environment and provide information and education on how to manage home-based care patients’ (Bonno), and:

The previous structure was fine because we were working with Family Welfare Educators, now their job description has changed, they are not doing many home visits. In the new structure they are Health Education Assistants. (Mmapula)

Participants felt that the loss of FWEs, who were trained community workers, created a gap in the delivery of home-based care. Their removal worsened already unpredictable workloads and staff shortages, which affected the delivery of quality home-based care: ‘Family Welfare Educators knew what they were doing, this was relieving us from worrying about home visits’ (Mmapula), and:

Before relocation it was easy because FWEs were doing home visits and they knew what they were supposed to do during home visits... but now it is difficult because we can’t visit patients, most visits are done by untrained volunteers. (Tshepang)

Transport difficulties due to the change of structure were part of the chaos reported by participants. They indicated that the previous structure was authorised by the local authorities. Consequently, if resources or transport were required for service provision, the council had the power to make the decision. Patients’ needs

were a sufficient rationale for hiring a car from locals who owned vehicles: ‘When we were under local government there was money allocated that we were using to pay the local people, such as councillors or anyone who had a car to transport the patient’ (Kate). After relocation, transport has become far more difficult to organise: ‘The relocation from Ministry of Local Government to Ministry of Health, things are hard for the District Health Teams because they have shortage of resources such as transport and staff’ (Taboka).

During the relocation, all vehicles belonging to the MLG were relocated to the MoH government fleet. Slow procurement or replacement of vehicles was mentioned by all participants as having contributed to the lack of available transport:

The issue of relocation from MLG to Ministry of Health gave us a problem, especially with transport, when we were at local government we had four vehicles just for home-based or palliative care. All these vehicles, when we relocated, we took them to central government. Now these vehicles are not used for the programme, they are used for administrative purposes or any other hospital-based duties. When you ask transport for home-based patients you are given a van to transport very sick patients. (Shirley)

Mmapula and Neo found it difficult to deal with the fact that staff allocation and vehicles were controlled by the DHMTs based at the hospital. That is, administrators who are not aware of needs ‘on the ground’:

It is hard, since relocation some of the things are managed from the hospital where the DHMT offices are based. Like here we have a serious problem of transport, very ill patients have been asked to catch a taxi from the clinic to the hospital because there will be no ambulance. (Mmapula)

And:

So this is really frustrating, all vehicles are managed from the hospital, even if you call the hospital there is very little assistance; this is a big village, it needs vehicles dedicated to this programme but now since the relocation we do not know what's happening. As nurses we are just moving with the confusion. (Neo)

Issues of patient safety and security during transfer were also seen as a problem. The need for patient security and safety during transfer to the hospital prevented nurses from personally assisting patients with transport where there was no ambulance or clinic vehicle. Although they were tempted to use their own vehicles to transport patients to hospital in their own vehicles, they were uninsured to do so, so were unable to assist:

We try our best but with no transport and few nurses it is hard, and nurses cannot use their vehicles to transport patients to the hospital because if they get involved in an accident, it is not right, they do not have insurance to transport patients, or if the patient dies in their car they will be held responsible. (Mmapula)

The further away from towns patients and nurses are located, the worse the difficulties. Kate, a remote-area nurse, raised her concern that nurses are working under difficult situations with no clinic vehicles: 'In this area, clinics are far apart but we have nurses who work where there are no good roads and the nurse does not have a clinic vehicle to transport patients' (Kate).

The lack of transport and time were significant barriers to nurses' ability to conduct home visits: 'We only visit patients when there is a vehicle, the relocation of primary healthcare services from Ministry of Local Government to Ministry of Health left CHBC programme without any transport allocated' (Kago).

Most participants viewed the lack of home visits as a sad occurrence that seriously affected them, emotionally. To know that the patient and family would be waiting for a visit that would not happen was distressing:

our experience is painful because you sometimes you see the patient once in a while (sometimes), you visit a patient once in a year and that will be all.

This is how it is, because there is no chance to do home-based care. (Bonno)

And:

When you visit patients in their home you have more time to see everyone.

Also you can understand the environment they live in which makes it easy for the nurse to support the patients. (Tshepo)

The nurses in towns and cities also faced challenges to their home visiting, but thought they were in a better position because they had support from other non-governmental organisations participating in palliative care:

To be honest, this town is a big place but we are lucky because there are many facilities they can go to. But I do not think they get quality care from government home-based care programme. (Neo)

4.2.4 Sub-theme 4: Lack of enjoyment

Participants' lack of job enjoyment and increased inclination to resign were issues raised by participants. The relocation of PHC services from MLG to the MoH

stimulated unhappiness among the nurses. Nurses reported that their work conditions were not conducive to providing quality and safe home-based palliative care. Bonno, a nurse who has worked in PHC clinics for many years, expressed the concern that PHC nurses were unhappy with the new structure: ‘Nurses are not happy and they are dissatisfied with the way home-based care is being managed, at times one thinks of just resigning’ (Bonno). Some participants reported a severe lack of motivation in their current role: ‘It frustrates us—we get demoralised’ (Kago). And: ‘I do not know whether we are demoralised by the new system or just that things have changed so much’ (Mmapula). And: ‘We are demoralised, we work very hard in home-based care but there are no incentives or job satisfaction’ (Shirley). And:

To tell you the truth, because the government has changed a lot of structures in home-based care, nurses are no longer interested in working in home-based care. Most of us just come to work but we are not motivated; it is frustrating. (Neo)

Participants observed that the lower numbers of available nurses were burdened with more roles, which they believed negatively affected the delivery of quality care to patients in the community:

As for manpower, we do not have enough nurses who are doing home-based care; these are the same nurses who are allocated in the clinic, they are not specifically for home-based care and this makes everything difficult. (Neo)

Palliative CHBC was not given priority, and participants felt that it was an ‘additional’ responsibility. When asked about where home visits fitted in their work schedule, one participant said:

Yes we do it as an additional duty because we do not have a nurse specific for home-based care and we do them, when there is a need we don't just visit, we only visit when there is a call out that there is a patient who needs to be visited. Otherwise I do not visit regularly. (Lebang)

Participants indicated that some clinics now operate 24-hour services, and nurses are involved in shift work. Nurses had to be either on night duty or afternoon shift, at the same time responsible for home-based care patients. Some indicated that they were not happy with the arrangement:

This 24 hour clinic, I do work night duty and at the same time I am supposed to be the focal person for home-based care, I am not happy because when I am on night duty or off duties no-one visits the patients. (Tshepang)

Another participant said:

We do home-based care as an additional duty, there is no nurse allocated specifically for home-based care. We only visit patients when there is a report from the volunteers or family members that the patient needs to be reviewed or is unwell. Otherwise we do not have regular visits. (Mmapula)

According to the participants, the daily problems they faced in delivering home-based care created a lot of stress, which negatively affected how they responded to patients. One participant indicated that this often resulted in the nurses losing a sense of control:

You know that thing alone can lead to stress for nurses and with stress they end up behaving in such a way that is not good. Their behaviour will be different, others will be shouting and some even reach out to those patients

saying they are tired and cannot be expected to go home and do this, this this... (Lebang)

When asked about the appropriateness of this behaviour, the participant replied:

No it is not acceptable but because nurses are tired and they are not satisfied, they have too much work at the clinic, no-one can blame them. For instance, if a nurse tells a home-based care patient that she is still busy with clinic duties, no-one can force her to leave what she is doing to attend home-based care patients. (Lebang)

Participants indicated that they did not find home-based care enjoyable anymore because the workload was excessive: 'The other stressor is the workload, because CHB care is not our only responsibility, we have other duties. The workload is too much' (Colleen).

Double counting or one nurse being allocated to both clinic roles and CHB care was reported to be an issue that needed to be addressed in order for nurses to appreciate and enjoy their work:

Another challenge is on staff. There is a shortage of staff, you find that I am a coordinator of home-based care and I am also allocated to work at the clinic; I am counted twice. When you come like you have come, I am still expected to attend to you. (Shirley)

The participants felt that, although CHBC was meant to reduce the workload of overstretched hospitals, excess workload was not reduced but effectively shifted to CHBC:

There will be too much work for the nurses even though the programme is designed to reduce workload, nurses are overloaded with work, they have no time to attend to home-based care patients. (Taboka)

Some participants believed that the excessive workload was caused by a lack of recognition of the value of home-based care under the new structure. For example, the nurses believed that other programmes such as the TB programme were more highly regarded, which created resentment among the home-based palliative care nurses:

Anyway, you think that why should I do it, it's an extra duty I am not paid for it and there is nothing to motivate me mmm... then there are other programmes like TB coordinator that's a programme, she/he will just focus on TB, she/he is not allocated any clinic duties, not doing any extra duties but just focused on TB... He/she will be only doing the TB programme, this is what we would like to see with home-based care, we can easily plan for the programme. (Shirley)

The burden of care thus placed on CHBC nurses was expressed in the following statement:

It is really a burden, it's really stressing even for volunteers, even other officers apart from the nurses, all officers who are involved in this programme, we are really crying. We are facing challenges. Challenges of transport it is very stressful... Now we are having backache because we have to take patients in a van, imagine. You have to bend on your knees, check

vital signs of patients inside. Doctors are refusing to check these patients from home; we have to. (Shirley)

Another source of unhappiness in the provision of home-based care is that there were patients who did not have any family or caregivers to assist them. Participants indicated that they often experienced frustration because they perceived that they lacked the time required to provide the type of care they feel is appropriate for patients who lived alone: 'Some clients will have come here looking for employment, then they get sick, then you find that this client is alone, as a nurse you are forced... make sure the environment is safe and clean before you leave' (Tshepang).

Patients registered under the Department of Social Welfare Services presented another challenge to the nurses. Social workers would provide them with food but there would be no-one to prepare the food or feed the patient. These activities came to be the responsibility of home-based care nurses:

Now the biggest problem is that some patients do not have relatives, they stay alone, but social workers from Social Community Development Services give them food but they still need someone to cook the food for them, help to feed them. The nurses are expected to visit and help with all of that. (Kago)

In some areas, the behaviour and attitudes of carers or family members were of concern to the participants. Nurses found that Batswana remote-area dwellers have a different lifestyle and exhibit different behaviours towards caring for the family member: 'Nurses are overwhelmed because at times, remote-area dwellers just leave the patients with no-one at home. There is a drinking problem; they wake up in the morning and go for drinking leaving the patient alone' (Kate).

In some situations, nurses found that some families actually abandoned the patients, and had nothing to do with their sick relative. Participants reported feeling pressured and obliged to provide care. Such situations were challenging, and not a job to look forward to: 'At times it is difficult, there are too many challenges because at times those patients, their relatives run away from them, they do not take care of them, which makes many nurses dislike working in home-based care' (Pretty). In some cases patients are rejected by their families because they have not been living with them in their home or in the community for a long time:

Here we have people who have no relatives, who do not have anyone to take care of them. Some left their villages long time ago and then Social and Community Development social workers help to identify where they came from and some relatives do not accept the client, so they end up on home-based care and destitute programme. (Lebang)

The breakdown of extended families due to the HIV/AIDS-related death of young adults has also left some elderly patients with no-one caring for them. The loss of family caregivers produces a gap that CHBC nurses cannot bridge:

Some patients do not have caregivers, I mean someone who stays with the patient, and you find that a patient stays by themselves, relatives are somewhere else. What happens now the volunteers and nurses have to alternate on checking the patients. (Shirley)

Participants indicated that it was not sustainable to expect home-based care providers to fill the gap left by family caregivers: 'Due to AIDS problem some people have

had more deaths in the family. Many frail patients will have no children of their own and relatives will not be will not be willing to take care of them' (Tshepo).

A major problem highlighted by participants was that in Botswana, if home care is not effective, there is nowhere else for patients to go. There are no nursing homes or institutionalised hospices in Botswana. Hospitals do not have room for long-term patient care: 'There is nowhere to take the patients because there are no nursing homes or hospices' (Lebang).

The struggle for the participants to fulfil their nursing obligations and duties under these circumstances was arduous. Participants felt trapped in a vicious circle of problems. They felt exhausted and tired: 'Nurses are just tired and frustrated from their work place, they are exhausted so after that they will be going to visit patients, ahh it's a burden. Nurses have stress due to this new system' (Tshepang).

Participants described juggling their daily clinic work and home-based care:

These are the challenges because if you are a home-based care nurse and you are alone at the clinic it's like *akere* (isn't it) you have to slot your time to visit the patients at home. At times you are going to be called that to come and see the client, but because of lack of time you rush there and do not do a good job because you have to go back to the clinic. At times you do not go, then assign another person or no-one goes. (Tshepo)

Some participants expressed concern that they felt helpless and burned out, and were contemplating resigning: 'Yaa it is hard and without passion, that's why nurses quit day one, you will be quitting but if you are doing it with a spirit of voluntarism that's when you will do it' (Shirley). And: 'We used to be active in home-based care programme but now nurses are reluctant to deliver care' (Mmapula). When asked the

reason for this comment, she said: 'I do not know whether [it] is because we are demoralised by the new system, or the workload without incentive' (Mmapula). Another participant said: 'Nurses are demoralised because things have changed, even to do home visits is very difficult. I do not like this job anymore' (Taboka). This participant's frustration was exemplified by the dismay she felt when family members or relatives stole the food supplied to the patient by welfare, and left without caring for the patient:

The patient stays alone, he is registered with Social and Community Development services, they provide him with food baskets. But some relatives just come to steal the food and go back to their home without even cooking for the patient. (Colleen)

However, some participants, when asked their views on community palliative care, had positive responses and felt that it was rewarding on a personal level. It was rewarding to observe how the patients and families appreciated the care they received. Although caring for palliative care patients at home had physical and emotional consequences, some participants reflected on their experiences as positive:

I have learnt to put myself in the shoes of someone who is having pain, either chronic pain or short-time pain. Yaa I have learnt to deal with a patient either chronic or not, home-based care has taught me a lot. (Shirley)

Some participants reported that they entered home-based care because they love the job and they want to help the patients:

For me I think it's okay but there are challenges. In community palliative care you get to interact with people, you feel you are doing something for the

community. The problem is the challenges that we face, first thing I do not have any training in palliative care. (Taboka)

The general feeling was that home visits offered an opportunity to know the patients better, and enabled a relationship to develop between the nurse, patient and family. These relationships sometimes formed over a long period, and the trust developed enabled acceptance of relevant assessment and assistance when families were in crisis.

When I visit patients at home and it has made me understand the patients and their problems as well as their home environment. I can understand the patient fully. Also when it comes to giving primary caregivers information without following them ahh some do not know what to do. Some patients use nappies and the caregivers do not dispose them properly, they pose as a public health problem. If the nurses visit they can advise the carers properly. (Tshepo)

4.3 Theme 2: Nurses struggling for advocacy

Optimal pain-management knowledge for nurses providing palliative CHBC to PLWHAs is critical for good patient outcomes, because pain and other symptoms occur throughout the progression of HIV/AIDS. Nurses, as frontline care providers, are faced with the challenge of alleviating symptoms. Based on the current study's literature review and findings, nurses' pain knowledge continues to be problematic, and is a limiting factor in advocating for effective patient care. Community nurses have a responsibility to patients but little power to affect how community palliative care is delivered in Botswana. Since advocacy is an integral part of nursing, it is

important that all practicing nurses are aware of their role in advocating for palliative care so that patients can be free from pain.

Lack of opioids and other pain medications effects health professionals' ability to effectively manage pain for CHBC patients in Botswana. Drug legislation, distribution and opioid phobia in Africa, in particular, have been major barriers to the use of opioids. Further, distance was found to have a negative effect on nurses working in palliative care in remote and rural areas, as access to resources and training became more limited as distance from urban centres increased.

Four sub-themes emerged from the theme of nurses' struggling for advocacy in dealing with community-based care in pain and symptom management:

- Perceived lack of power;
- Perceived lack of knowledge;
- Perceived lack of resources;
- Perceived lack of continuity of care.

4.3.1 Sub-theme 1: Perceived lack of power

From the participants' narratives, it was clear that they experienced feelings of helplessness in advocating for appropriate care for patients receiving palliative care at home: 'Since we are not palliative care nurses we cannot argue much, though we would like to advocate for our patients. We do not want patients to suffer' (Lebang). Participants reported their frustration and feelings of helplessness based on what they observed in their daily practice, and recounted stories about patients who they believed suffered severe pain while under the care of doctors: 'We tried to advocate for this patient, he gave her hydrocortisone and said the patient can wait

outside... We tried to emphasise the fact that doctor, are you aware of the patient's condition?' (Kago).

The participants reported feeling inadequate in their role as patient advocates, especially in situations where they believed doctors were avoiding prescribing appropriate pain relief: 'I feel we do not have authority to influence the decisions of doctors about patients receiving home-based care' (Bonno). Participants reported feeling vulnerable in patients' homes while they observed them suffering from untreated pain, because there was nothing they could do to relieve it: 'Even if we knew what to do we see patients suffering from severe pain when there is nothing we can offer except to give them paracetamol and reassurance' (Kago).

Participants reported that lack of knowledge of palliative care affected their ability to speak on behalf of home-based patients, because they lacked confidence: 'Due to lack of training and lack of adequate knowledge on palliative care we are reluctant to speak on behalf of patients who were not receiving strong pain tablets' (Taboka). And: 'Though I have been caring for home palliative care patients, unfortunately I do not feel comfortable and confident to convince the doctors to prescribe opioids' (Lebang). Participants' suggested that they needed better training in palliative care in order to equip them with the knowledge and skills necessary to be effective patient advocates: 'In order to improve our level of confidence we need more training on palliative care or exposure on various palliative care issues, caring home-based palliative care patients, including PLWHAs' (Bonno).

The participants were concerned that palliative care guidelines were available but they felt that doctors disregarded them. The disregard of guidelines was viewed as the government's reluctance to practically enforce policies:

Even in pain management the situation is whereby doctors refuse to give opioids, it's a known fact, but no-one seems to be doing anything about it. The palliative care guidelines clearly say that patients should be given morphine or codeine. (Neo)

Participants observed that most patients were not prescribed any opioids:

Ahh you know it is sad the time the patients take suffering in pain without any relief is very sad for us. With us it is even sadder because we have a doctor around. The problem is we cannot change the doctor's views about prescribing morphine. Hey! Nurses' cannot do much because they do not have much power. (Kago)

And: 'The doctor here will not prescribe any morphine unless if the patient has come with it from hospital' (Kate).

Most participants observed that doctors managing clinics usually refused to prescribe morphine to patients who were in pain until it was very late: 'I think because they have worked more in the hospitals they often separate curative from palliative care. Consequently, they withhold adequate pain relief until the patient is very ill. This adds to unnecessary patient suffering' (Neo). The participants believed that they should have the authority to prescribe necessary medications to adequately relieve pain and suffering:

If we were given the mandate to prescribe medications I think it was going to solve the problem. I think it was going to be better because we were going to manage those patients the way we feel they need to be managed, not to rely

on someone. Because it is us who see visit on daily basis, but if someone is far or if talk to the doctor they do not do anything. (Kago)

Something that stood out in these interviews was that the majority of nurses communicated a sense of inadequate control over their own work and patients' situations in the community: 'The patients in the community do not receive adequate clinical attention/care from us. I feel that we do not have enough control over the care of community home-based patients' (Neo).

4.3.2 Sub-theme 2: Perceived lack of knowledge

The participants felt that they were not knowledgeable about palliative care in Botswana: 'We try hard but it is hard because we don't have an in-depth understanding of palliative care, what I know is that it is only about death and dying' (Lebang). Participants felt that if they could be adequately trained in palliative care and left to practice according to their professional capability, they could achieve maximum symptom control for home-based palliative patients, and better advocate for their needs: 'Sometimes I feel nurses have limited authority over patients who are cared for at home, if we could be left to take charge of patients without a lot of barriers, patients care would be appropriately delivered' (Tshepang). And: 'I cannot express exactly what I am lacking even though I attended some workshop I don't feel adequately equipped to deal with terminally-ill patients at home' (Tshepo). The participants suggested that their low knowledge would be improved by increased training: 'The training we received was conducted in two weeks, then there was no follow-up' (Josefa). And: 'In my observation the palliative care knowledge I have is not enough, the training we received from a workshop was not adequate to make me feel confident enough to deal with terminally-ill patients at home' (Shirley).

The need for proper pain assessment procedures was one issue identified by participants. They revealed that they were aware of their responsibility to ensure that patients who were in pain were adequately assessed and managed. Participants indicated that underassessment of pain was due to lack of knowledge and use of pain assessment strategies:

I feel there is no pain assessment, though we know that proper pain assessment helps nurses and doctors to treat the patients' pain accordingly. We should be following the WHO pain-management ladder but we are not... because the programme says patients in pain must be given codeine at home level, but you find that they do not get it. (Josefa)

And:

Sometimes it's due to nurses' and doctors' lack of understanding of pain assessment tools. It is painful if I can cite the example of this old lady, she came here sometime last week, was screaming on this floor. We called the doctor and said doctor why can't you write this patient morphine because she is in pain, she needs something stronger, but there was nothing we could do. (Kago)

The inadequacies in pain assessment were also associated with time constraints and nurses' work pressure:

Somehow you have to follow these patients at home at the same time leaving your clinic duties unattended to. You know the way we do it is not proper because we have to rush through without doing full assessments, we do not take time with them because we have to rush back to the clinic. (Mmapula)

Further focusing on training needs, nurses identified the need to train volunteers in the assessment of pain. Nurses recognised that volunteers were mostly involved with patients at home:

We now must teach our health workers on pain assessment and pain management, even the need for follow-up. I think the follow-up is not enough, we need reliable transport to be able to visit clients and try to reassess, sometimes it will be major pain but maybe tomorrow will be minor pain. If you assess them regularly you can manage their pain. (Tshepo)

Participants indicated that doctors' fears of possible opioid abuse resulted in pain being under-treated. Opioid analgesics were viewed by participants as the primary therapy for relieving pain if properly titrated. Therefore, nurses felt that improving doctors' and nurses' knowledge on titrating opioids would minimise the fears of addiction and benefit the patients: 'Pain has to be controlled, what we were told during training was that there was no limit to administering painkillers to patients with severe pain if it is properly titrated and observing side-effects' (Neo).

From the participants' narratives, it was evident that while providing care to patients receiving home-based palliative they experienced a series of obstacles in dispensing appropriate, strong analgesics. These obstacles included both the lack of availability of opioids, and the lack of prescription by doctors. The nurses felt that doctors were not comfortable with, or had fears regarding the prescription of, opioids due to their lack of knowledge on them:

Some doctors I think do not have enough knowledge on the use of opioids, therefore are uncomfortable and felt that patients will get addiction, for

example we had this patient with cancer of the nose, she was on codeine phosphate and when it ran out we gave the patient paracetamol. (Kago)

The participants' views were that if doctors were sufficiently cognisant they would not choose to tolerate patients' suffering of under-treated pain due to fear of addiction: 'People seem to be uncomfortable with giving morphine at home level, they think they are drugs that are addictive. Due to inadequate knowledge, nurses, doctors and pharmacists have a problem with prescribing opioids to home-based care patients' (Josefa).

Participants expressed a strong view that if doctors had been trained and experienced in community work, they would improve the continuation of care at home to prevent prolonging patients' suffering: 'The doctors are the problem in some facilities; doctors are trained, but they still do not prescribe opioids' (Josefa). And: 'We still have doctors who cannot prescribe opioids because they are not comfortable and are concerned about addiction' (Neo).

4.3.3 Sub-theme 3: Perceived lack of resources

Participants identified lack of human and material resources as key factors in the poor delivery of home-based palliative care. They perceived that the MoH was grappling with how to effectively provide resources to local health authorities. They also reported difficulties related to the MoH not adequately overseeing healthcare logistics at the community level. Shirley felt that because the central government had not previously implemented community palliative care, it had no idea of how to adequately maintain the resources required for its efficient delivery:

Last year we had a challenge, we did not have continence aids. The relocation gave us... it strained us. Central government did not have this

programme, it was challenging for them to own this programme even to fully understand how to proceed with home-based care.

Material resource shortages affected many aspects of the delivery of home-based palliative care. Nurses felt helpless regarding problems associated with shortages of resources such as gloves and medications: ‘My only worry is what we see happening with patients at home. There was a time there were no gloves, no medications, what do we do as nurses?’ (Kate).

Nurses attributed the lack of adequate material support for home-based care to the advent of ARV drugs. As most patients now ‘get better’ or do not decline as quickly, the government has moved its focus away from community-based care for HIV/AIDS patients: ‘This programme, it seems since the number of AIDS patients has gone down due to ARVs the programme is not much supported’ (Neo). Due to the lack of adequate resources participants were concerned about unsafe practices. They believed that the decrease in the availability of protective clothing as a result of relocation was dangerous in situations where volunteers and primary caregivers had to provide care to HIV/AIDS-infected patients. When there were no gloves, family caregivers and volunteers were left with no option but to attend to patients without any protection, even when they would be exposed to bodily fluids:

Last year during relocation there was a time when we did not have gloves and other resources, it was hard to go into the community and attend to patients without adequate protective clothing. We were feeling sad for the volunteers and families because there were no gloves but some of the patients on home-based care are HIV-positive, but the volunteers, they try their best to help the patients even with no protection. (Kago)

Not only did nurses struggle with a lack of supplies, but also with volunteers' lack of knowledge about infection control. Volunteers' attitudes towards the use of gloves when they did not know the patients' HIV status were perceived to be inappropriate: 'The problem sometimes is with carers and volunteers, because in some instances when they are not aware of the HIV statuses of the patient tend not to use gloves thinking the patient will feel that they are shunning him/her' (Bonno). One participant preferred that the clinic share gloves with the caregivers and volunteers, but advised them to take precautions in situations where other protective measures were needed:

Concerning gloves, we try by all means to share the clinic supplies with volunteers and family caregivers, but we advise them that where they need things like aprons and shoe protection they must take extra protection not to expose themselves to blood and other body fluids. (Colleen)

Infection control in health facilities and in the homes was also an issue of concern to the nurses:

The other challenge is shortage of commodities, we always run short of nappies, gloves, detergents such as *jik* and soaps. And another problem we have is a big challenge of the disposal of nappies because since the relocation of the programme around 2006 they used to provide dustbins at home, then the council go and collect but that thing has stopped and these people do not have a place to dispose the nappies. Somehow they were told to dispose them at the clinic and the clinic does not have dustbins, they do not have disposal sites. For the nappies, that one is a big challenge. It's a problem between the community and staff. (Mmapula)

Some nurses considered the transfer of patients from home to hospital or to the clinic for review to be unsafe. Participants stated that while at home they do not have lifting devices, so they are compelled to lift patients themselves:

Doctors are reluctant to check these patients from home, we have to take the patient to the clinic in a Hilux, to load and off-load this patient we have no lifting devices. Now we have backaches because some patients are heavy.

(Shirley)

And: ‘The volunteers are the ones doing the job, but they are not trained on lifting techniques. These are old people, they lift patients which I [feel is] not good for them and the nurses’ (Mmapula). The vehicles they use to transport patients were not suitable, and hospital administrators did not accept the need for ambulances at clinics: ‘We do not have proper ambulances to transport patients from home to the clinic or from the clinic to the hospital’ (Mmapula).

4.3.4 Sub-theme 4: Perceived lack of continuity of care

Participants were concerned about the transition of patients from hospital to community care, and about flawed discharge procedures. Poor discharge communication resulted in patients not being identified by the local clinics, causing delays in care because the clinic nurses did not have any information on proper follow-up arrangements. The participants indicated that the problem occurred more frequently with rural and remote patients:

Another thing I do not know because we have not had a chance of working at the hospital, it’s like we do not have a discharge plan, to say we have this patient we want to send home on palliative care. The discharging facility can

communicate with the local clinic that there is a patient on palliative care who is being discharged and send the referral letter to the clinic or DHT.

(Kate)

Participants who did receive some form of referral from the hospital expressed concerns with the delays in receiving the information: ‘The timing of referrals from hospital to home-based palliative care is too lengthy, at times we just find patients at home before we can even receive the discharge summaries and referral letters’ (Colleen). Without information, nurses had minimal guidance on providing continuity of care: ‘Improving communication between the discharging hospital, DHMT and the receiving clinic may be a better solution to late referrals for home-based palliative care patients’ (Kate).

An important finding was that nurses felt that when the government discharged patients, especially to remote locations, it was just like releasing them to go and die without effective care: ‘from my observation, when patients are discharged from hospital they stop giving them strong pain medicine immediately because most of the patients I have seen, I haven’t seen those on morphine at home’ (Tshepo). And:

Again, most of the time once they are discharged from hospital they do not last they just ehh... most of them the patient can go up to a month... After a week they die, maybe it’s because of pain, that’s why patients die sooner than expected. (Kate)

Lack of opioids in the communities, particularly in remote and rural areas, led to interrupted care. The pharmacological prevention and management of pain requires supplies that allow clinicians to prescribe and dispense. Nurses indicated

that the lack of opioids in rural and remote clinics was detrimental to continued care of patients post-discharge. However, participants put the blame on Botswana legislation, which is overly restrictive about the prescription and storage of opioids: ‘The restriction of drug storage is a problem that needs to be resolved, in this clinic we do not have a dangerous drug cupboard, so we cannot stock any opioids’ (Colleen). In the rural and remote clinics nurses suggested that it would be better to be flexible and provide each clinic with a dangerous drug cupboard and trust that the nurses would keep the drugs safe: ‘I think now it’s time for the government to acknowledge that us nurses are capable of keeping the drugs safe under lock and have the drug log books to sign for the medications’ (Tshepo).

Participants were surprised that patients were discharged without any strong pain medications. They felt that opioids should be prescribed as part of on-going care while patients were back in the community. Discharging patients to the community where facilities did not have opioids and expecting them to do without any strong pain relief was considered by the participants to be a violation of the patients’ fundamental right to freedom from pain: ‘I can’t just imagine that patients are discharged to go to the villages where the doctors in the hospital know that there are no strong analgesics, this all left to the nurses to deal with’ (Tshepang).

Participants indicated that the restrictions on only allowing doctors and pharmacists to prescribe opioids was not applicable in all healthcare settings, as some facilities did not have such practitioners. This drastically compromises the ability of nurses to manage patients’ pain: ‘The government has laws that it is only the pharmacist and doctors who can prescribe and dispense opioids. It is not realistic because most of the clinics do not have doctors’ (Neo).

The provision of codeine phosphate was attributed to be effective for some patients, and family members were satisfied with this intervention when effective: ‘Some families that I have visited or have come to the clinic to get the patients’ medicines have reported that if a patient takes the small white tablet at night they sleep better’ (Lebang).

Doctors’ lack of experience in CHBC was viewed by participants as contributing to the lack of continuity in patient care when they returned home. The participants indicated that new doctors with a hospital orientation did not seem to pay much attention to the patients at home.

For the doctors who are not PHC-oriented it is hard because at times they do not even agree to go and see patients at home, saying they are busy, but these are the people trained in palliative care. Even if they do not go and see the patient at least they are supposed to prescribe something for pain. (Neo)

And:

Sometimes the nurses perceived doctor neglect was due to overwork. When patients are discharged on home-based care to continue with their care, nurses, doctors and social workers are supposed to visit the patients. But this sometimes does not happen, sometimes nurses do but as for doctors they do not have the time. (Shirley)

Side-effects were also viewed as a possible reason for discontinuing symptom management. Participants acknowledged that patients and relatives might become uncomfortable when patients taking codeine phosphate at home developed

constipation, and for this reason the level of patient resistance to taking the medications was significant:

Again, when it comes to managing patients' pain, you find that sometimes as a nurse you are torn in between because this client is having pain and at the same time the analgesics give them constipation, and once constipated they refuse to eat. (Colleen)

Participants mentioned that they used liquid paraffin, but it appears to not always work: 'We give liquid paraffin but sometimes patients still complain' (Colleen).

4.3.5 Conclusion

The findings showed that there were knowledge deficiencies among nurses in the delivery of palliative care to home-based care patients. While there was good understanding of what constitutes CHB care and nurses were willing to provide care for home-based care patients, they indicated that they were not adequately trained to deal with palliative care patients at home. Nurses' narratives suggested that they had limited opportunities for education in palliative care. Findings indicated that nurses' lack of educational preparation in palliative care rendered patients vulnerable to inadequate care, particularly pain and symptom management. Nurses' frustration when their concerns were not acknowledged by doctors contributed to their perception of the under-treatment of home-based care patients. Nurses' feelings of powerlessness affected their level of practice and confidence.

4.4 Theme 3: Nurses Dealing with HIV/AIDS Stigma and Discrimination

Genberg et al. characterised stigma as an attribute that is deeply discrediting and which leads an individual to occupy a tarnished and discrediting identity and place in society. The pervasiveness of stigma in Botswana is important and difficult to completely eliminate, because what has been embedded cannot be easily taken away. In some instances, PLWHAs are assumed to have contributed to the situation they are in (Genberg et al., 2008, p.772).

Despite the Government of Botswana's significant interventions into addressing stigma and discrimination, stigma still manifested in different forms, and continues to present a barrier to effectively fighting the disease. However, the findings suggest that although the common association of negative moral values with PLWHAs remains and perpetuates some forms of stigma, the advent of ARV therapy has helped to mitigate the impact on PLWHAs.

Discrimination against PLWHAs resulted in poor quality care for those infected or suspected to be, frightening away clients in need of care and undermining effective HIV prevention efforts (Young et al., 2010). This study established that fear of discrimination prevented PLWHAs particularly nurses from seeking treatment for AIDS or from publicly admitting their HIV status. At the individual level, the internalisation of societal responses to PLWHAs and its resultant fear may result in individuals isolating themselves from accessing treatment and care (Williams, 2014). HIV/AIDS stigma has been expressed in a variety of ways, including ostracism, rejection and avoidance of PLWHAs. When a person is labelled by their illness they are seen as part of a stereotyped group. Negative attitudes create

prejudice, which leads to negative actions and discrimination (Stephney & Prosalendis, 2005, p. 1). Stigma was certainly an impediment to HIV-positive nurses accessing available government-initiated HIV/AIDS programmes.

Four sub-themes emerged from the theme of nurses' dealing with HIV/AIDS stigma and discrimination:

- Negative attitudes in the community.
- Community shame and blame.
- Nurses' fear of ostracism.
- The role of ARVs in reducing stigma.

4.4.1 Sub-theme 1: Community negative attitudes

Participants indicated that at first, stigmatising behaviours towards PLWHAs were prevalent because HIV/AIDS transmission was associated with prostitution. Sufferers were believed to have contracted the disease through morally questionable practices. The participants reported that the way HIV/AIDS was introduced fuelled the spread of discrimination in Botswana, and it would take time to de-stigmatise the disease. Infected people were fearful of being blamed for how their condition occurred, making them less likely to seek treatment: 'Stigma is still here, I think it is because of how it was introduced, how people were told about HIV, that it is a sexually transmitted disease and only immoral people get it' (Taboka). And: 'Some form of stigma and discrimination is still there, we can't run away from that one. We still have patients who do not want to be seen or known that they are HIV-positive... it impacts our work' (Neo).

Participants observed that HIV/AIDS was stigmatised because it carried symbolic associations of danger. The participants believed that what fuelled stigma

at its onset was that AIDS was associated with death, and the government did not concentrate on curbing the stigma:

It was hard to deal with the fact that this person was dying from a highly infectious and incurable disease and the measures put in place to prevent the spread of the virus I think also contributed to the discrimination of PLWHAs.
(Bonno)

Participants observed that in most people who displayed negative attitudes towards PLWHAs, the reaction was caused by a fear of contracting infection: 'Fear is a big thing, most people, including health workers, do not choose to avoid the patients but they just do it out of fear of infection' (Kate).

Most participants believed that negative attitudes towards PLWHAs would take a long time to dispel:

I don't know but I think many people who have been diagnosed HIV-positive find it hard because this has been going on since the first AIDS case; at times it's like you have committed a crime. The community will regard you as a loose person, especially for women. So PLWHAs have a genuine cause for fear. (Kago)

Participants found that in the past, due to the stereotyping associated with HIV/AIDS, PLWHAs in home-based care and their families were not comfortable with visits from nurses or healthcare providers. Participants reported that some families still preferred not to be visited by health workers, even if there was a palliative care patient in their home.

Ahh some families do not like health workers coming to their home because in the past home-based care was associated with AIDS patients, so they do not feel comfortable. I think they felt that other people and neighbours will think they have an AIDS patient. (Taboka)

Participants indicated that the negative depiction of PLWHAs in Botswana through labelling and use of derogative language to describe the disease has reinforced the negative attitudes held by some families: ‘Some relatives or family members might take long before they can accept the patient. Some do not want to be associated with an AIDS illness in the family’ (Taboka). Negative attitudes in the community fuelled secrecy and prevented some from seeking treatment: ‘Stigma is still there even if people have understood, but because of the people’s attitudes, this still prevents some PLWHAs from coming to the clinic or allowing nurses to visit’ (Taboka).

Negative attitudes about HIV discouraged PLWHAs from seeking timely assistance, and prevented them from reporting freely. This affected nurses and volunteers to such a degree that some volunteers preferred to be anonymous, for fear of being victimised by families:

Volunteers sometimes struggling to report the possibility of HIV/AIDS to nurses without fear of being accused of gossip by the families. The participants reported that families fear to be discriminated because a lot of people still display negative attitudes towards PLWHAs. (Colleen)

Other situations can trigger community discrimination, such as multi-drug resistant strains of TB. Patients suffering from this displayed similar symptoms to those of AIDS. This problem has recently emerged in Botswana: ‘And again now

this home-based care... it's not only HIV-positive patients, there is TB, which is also ending up with multi-drug resistance. So, we have to continue talking about stigma and discrimination' (Neo).

According to participants there were still some isolated cases of stigma and discrimination towards patients receiving home-based palliative care, regardless of their HIV status:

Even if stigma is less during some of my home visits, I found at one place where a patient who was not HIV-positive but was enrolled on home-based care and receiving food baskets, what I realised was that this patient was always isolated, she was always alone in the house. Because she was very ill the family had concluded that she was one of the AIDS patients. (Kate)

4.4.2 Sub-theme 2: Community shame and secrecy

Although stigma had decreased at the time of the study, the overall picture from nurses' narratives indicated that PLWHAs, including infected nurses, still felt guilt and shame. The shame regarding their HIV-positive status contributed to their reluctance to access HIV/AIDS services:

There are patients who do not want to come to the clinic. But when we follow them you find that this is a really sick patient who has been in the house for five days without eating, in pain, afraid of stigmatising him or herself if they go to a clinic. Not going to the hospital. It's good that the community nurses and the volunteers can do this. (Shirley)

The participants' narratives suggested that, due to shame, not only would infected PLWHAs isolate themselves but their families as well. Some families were

said to have prevented patients from accessing health services out of shame: 'Some families prefer to hide the patient and not come to get treatment for the patient, especially those who are middle class, because of shame and not wanting to be associated with HIV/AIDS' (Taboka).

Participants suggested that shame manifested as anger and even abuse of HIV-infected patients. Family can stigmatise and neglect children receiving palliative care because of their HIV diagnosis:

Stigma is there, we once had this woman who was taking care of her sick grandchild. Four of her children had died of AIDS leaving children under her care. One of the grandchildren was infected. The grandmother was very angry and furious. When we visited her she did not want to see or hear anything from health workers. Her neighbours reported to the clinic that that every morning she drags this child outside the house and in the evening drags the blanket back into the house. She did not want to be helped by the home-based care volunteers. As the child's condition deteriorated the pastor went and brought the child to the clinic; we sent the child to hospital. The grandmother did not visit the child at the hospital; she was blaming the pastor for sending the child to the hospital. The child died in hospital. (Bonno)

And:

Family members of this child at first were supportive but when his mother died and cause of death was AIDS-related illness, I think they changed then, after her death when her son became ill, but when the relatives brought him to the clinic the child's auntie said in a harsh voice, I have brought this child, check him, check everything. That's when I realised that she was not talking

nicely in front of the child and again I never used to find this lady at home while we were caring for her sister. I concluded from the way she was behaving that she was stigmatising the child because his mother died of AIDS. I concluded that she did not care about her dead sister, she was stigmatising her because of HIV. (Tshepang)

4.4.3 Sub-theme 3: Nurses' fear of ostracism

Because of their perceived position in society, participants feared that nurses who become infected with HIV would be subjected to even greater discrimination than other PLWHAs. Community standards for nurses are higher than standards for others. The widespread belief in communities that HIV/AIDS is the result of immoral conduct has adversely affected the lives of HIV-positive nurses. Also, the fear of discrimination that they have often observed as caregivers can induce self-stigmatisation in nurses, even before their illness is revealed to others. Internal stigma was considered to destroy the nurses' ability to cope, and increased nurses' concerns about being identified as positive: 'Aah I feel nurses are stigmatising themselves because they see other PLWHAs being discussed by health workers using some negative or derogatory language. They worry about who will know their status' (Tshepang).

The narrative suggested that nurses were part of general society and general perceptions and attitudes towards PLWHAs influenced how they viewed HIV/AIDS patients. If AIDS was viewed as a normal disease, nurses could feel more comfortable with their own status. They found that labelling and use of derogative terminology to describe PLWHAs in health facilities still existed: 'There is a tendency among health workers to label or use some derogative terms to describe

PLWHAs, names such as *phamo kate*' (Kago). Out of fear of being talked about and judged, HIV-positive nurses were said to prefer to keep their information secret from other nurses who may cause them to feel isolated and alienated. Gossip among nurses was said to increase the silence around nurses suspected of being HIV-positive:

The thing is, once the diagnosis is known everybody will know. Nurses and other health workers for the first few months will talk about it. Till it is no longer news of any concern, but the fact is everyone will be aware, even those who have nothing to do with care of the PLWHAs. (Bonno)

Internal stigma was perceived to have produced some suspicion among infected nurses, as was increased consciousness about their physical appearance (as it would confirm the diagnosis of HIV). Stigma destroyed nurses' confidence. Tshepo gave an example of how he felt stigmatised, even as a sufferer of another disease: 'Concerning stigma, sometimes is just how the person feels, like I once lost weight, was diagnosed with pulmonary tuberculosis, but every time people look at me I felt like they were talking about me that I was HIV-positive' (Tshepo)

Participants' lack of communication with other nurses about their HIV status was attributed to fear. Participants perceived no adequate support for HIV/AIDS-infected health workers in terms of their individual HIV-positive status. Therefore, nurses did not find it helpful to talk to other health professionals about their status:

I am going to say my observation, we nurses are the worst enemies of ourselves, nurses are not supportive when it comes to colleagues and a nurse would rather go to a different place to test because you are afraid that my colleagues might not accept me. (Kate)

When I asked, ‘Do you know any nurses who are HIV-positive?’ Tshepang said:

I know that there are HIV-positive nurses, like we all talk about it, but I haven’t come across one who has confirmed their HIV-positive status to me. My observation is that any nurse who gets a positive status decides to be discrete about it.

Only one participant said she knew of a nurse who revealed her HIV-positive status, and was now receiving ARV therapy from the local IDCC:

Since I came into this programme I can’t say there is someone I know... I can’t remember any nurse who was affected. Ohh no... I know one nurse because I found her, here she is the only one... She takes her medication here. (Pretty)

Confidentiality was acknowledged as standard procedure among most nurses in the study. The secrecy and silence of nurses perceived to be knowledgeable about epidemiology and control of HIV about their own status was considered unhelpful, as the nurse participants are supposed to be at the forefront of the fight against discrimination: ‘It is sad because nurses are the ones who should be educating the community about the progression and controlling of the virus, but if they are not free to talk about themselves it makes everything hard’ (Josefa). And: ‘That is their right to withhold information but it can also be a big setback to educating the public if nurses are not free to talk about HIV-positive status’ (Neo).

Participants argued that these attitudes could be traced to the prejudice that PLWHAs are promiscuous: ‘Stigma is still there, we can’t run away from that. This is from how health messages were initially delivered that people with HIV/AIDS had

multiple partners and it is a sexual transmitted disease' (Neo). As a result of the participants' perceptions, fear of stigma and discrimination led to silence and the suppression of all discussion about HIV/AIDS:

So, you find that even us at DHMT we call meetings to support one another, we share general things like managing our finances but when it comes to... but there is still a problem with nurses, I think nurses we need counselling. We always think we know but when it happens to you realise that eeh... this is now different. (Kate)

Participants suggested that nurses struggled with self-stigma regarding HIV diagnosis, which even led to a lack of care taking precautions after occupational exposure to bodily fluids:

This is difficult... they do not want to test even if one has a needle stick injury, they would rather keep quiet and not report because if they report they are required to have a test for Post Exposure Prophylaxis. (Tshepo)

Fear of discrimination was said to have prevented nurses from accessing available government services. Participants' believed that infected nurses were in denial by refusing to come forwards and use this programme: 'a lot of nurses are in denial, they don't want anyone to know that they are HIV-positive. So it will be hard for them to seek support from the available services' (Taboka). And: 'Even though there is a care-for-carers programme, which is meant to support nurses. I don't think the HIV-positive nurses are open enough to utilise the services' (Kate). And:

Some nurses do not even want to be registered on home-based care when they are able to give consent. Some you find that they will be registered

because they are no longer capable of giving consent, somebody has to do it.

But hela as an individual when they are still able they do not give consent.

(Shirley)

Fear of discrimination was said to have led to concealed or aborted treatment, when nurses' medical aid funds ran out:

Hey it's plenty, it's there among health workers, because sometimes we diagnose them clinically. Nurses do not disclose at the time, we just hear that there is somebody who is working with you, she is defaulting from medication. Maybe, it's not easy for nurses. (Tshepang)

And:

There was a colleague who was diagnosed with HIV three years ago, and was started on HAART from another facility, but now we hear that she is defaulting from taking treatment because she has exhausted her medical aid for this year, but she will not access the free services. (Tshepang)

Participants who were infected were reluctant to access the free services at the local community clinics when their private funding expired due to the fear of being identified. Their narratives suggested that some nurses were so concerned about being identified as HIV-positive that they risked death rather than seek help at the local community clinics: 'Nurses die of AIDS because of lack of being free to access services. They prefer to go to private doctors but when the medical aid funds are exhausted, they default from taking treatment' (Neo). And: 'Majority of the nurses who are PLWHAs are not free to register for home-based care, they wait till it is too late when they are very sick and relatives ask for help' (Shirley).

Participants believed that government support for infected nurses was lacking. They indicated the need for the government to protect their right to privacy in the context of HIV/AIDS, and felt there were not enough precautions to protect those infected from being discriminated against: ‘the government has to ensure that healthcare institutions enact strategies to protect the health workers’ privacy’ (Tshepo). And: ‘I think to maintain the nurses’ confidentiality there should be clear policies and actions taken against those who violate other people’s rights by discussing their diagnosis’ (Mmapula).

Participants also observed that the MoH was not very supportive of the nurses: ‘The health sector is very poor in supporting nurses, so nurses prefer to suffer in silence’ (Taboka). One participant stated that some support mechanisms are in place but due to lack of disclosure, nurses do not fully utilise the services: ‘Botswana Nurses Association has a care-for-carers programme which is meant to support nurses, but due to fear of stigma and discrimination I don’t think there are many PLWHA nurses who access the services’ (Kate).

4.4.4 Sub-theme 4: Role of ARVs in reducing stigma

From the participants’ narratives, it was clear that commencing ARVs early and maintaining adherence to the drugs helped prevent or delay HIV-positive people progressing to AIDS, thus increasing their lifespans. This also reduced community stigma by ‘normalising’ the disease:

The picture for now, because since the introduction of ARVs I would say most clients are up and about; we do not deal with clients who are bedbound due to HIV anymore. Because basically if we see that they are HIV-positive we take their CD4 and count and refer them to the ARV clinic. (Josefa)

Conversely, nurses indicated that poor adherence to ARV therapy was a challenge for PLWHAs, and can trigger the progression of the HIV to an AIDS-related illness, resulting in PLWHAs experiencing discrimination and social isolation: ‘They take ARVs but once they are healthy they feel they are fine, they stop taking them. Then they progress to AIDS, that is when people talk about them: some talk in a negative way’ (Neo).

According to the participants, ARVs have proven successful in enhancing PLWHAs’ quality of life and has instilled hope in them. As the HIV/AIDS epidemic has progressed and the availability of ARVs increased, it became apparent to the nurses that people were becoming more relaxed about HIV diagnosis:

For PLWHAs, it is no longer strenuous and they are accessing services unlike when it started, those times ARVs were not there. With HIV, you find that nowadays somebody will be down today, you go and check after they have started ARVs then follow-up maybe after a month you find that the person is now up, except for those who already have complications related to AIDS.

(Kate)

And: ‘Yaa it’s no longer as heavy, even the public understands at first patients were suffering, relatives would just eat their food basket and then neglect them. But nowadays they know the patient will recover once they start taking ARVs’

(Tshepang).

Thus, with concentrated community education and the advent of ARVs, community members and families have become more accepting of the delivery of palliative care at home: ‘In the community now stigma is much less, it’s not like before *kana*,

before when they saw the ambulance they were always curious to know what was happening' (Pretty). And:

It's not like in the past; the person would get sick and die. If the patient gets sick now, relatives will call the nurses and say your patient is having...

[symptoms]... they are not afraid to ask for help. (Tshepo)

The decline in stigma has reduced the sense of community isolation among PLWHAs and their families, because neighbours were also in a position to check on the patients: 'They are able to check each other, when someone refuses to come to the clinic they will come and say my neighbour doesn't look fine, I have come to report, nurse go and check on him/her' (Shirley).

4.4.5 Conclusion

Despite the widespread recognition of discriminatory treatment of PLWHAs in Botswana by society, nurses felt that the government has had limited success in alleviating the effects of stigma, which results in the negative attitudes of neighbours, family, health workers and society at large. The findings revealed that in situations in which discriminatory practices were observed, families not only hid the patients but also denied them necessary care. This resulted in social isolation for patients and their families. Poor family attitudes towards PLWHAs (even children) still cause concern for nurses. Stigma was perceived to prevent the delivery of effective care, including access to ARV and also enhanced a number of HIV infections (Mbonu et al., 2009).

A significant number of participants reported that discriminatory attitudes and behaviours towards HIV-positive nurses were still widespread. Such prejudice, or the fear of it, hindered nurses from disclosing their HIV status or utilising

government HIV-care programmes. Fear of a breach of confidentiality among nurses was high. Most participants believed that nurses were not ready to test or disclose, and even if they were unwell, were not ready to undertake treatment, even when they were very ill and required palliative services. Participants shared concerns about the lack of support among their colleagues, but it was considered difficult to offer support because HIV-positive nurses kept their status confidential. Thus, it appears vital that attitudes promoting nurses' fear and avoidance of discussing HIV/AIDS needs to be addressed.

Participants indicated that ostracism and discrimination has been a huge problem in the identification and treatment of HIV/AIDS patients in Botswana in the past. However, the general feeling among nurses was that, due to the presence of ARVs, stigma has been greatly reduced.

With the advent of ARV therapy, PLWHAs found hope to rebuild their lives, and those on ARV with good compliance continued with their normal life. Results suggested that effective HIV/AIDS treatment has transformed the face of HIV/AIDS in Botswana. The availability of ARVs has changed the public perception of the disease and has helped reduce stigma. However, conclusion was that patients who experience some form of stigma because of the disease progression might still be inclined to reject treatment.

4.5 Theme 4: Nurses Committed to Support Volunteers

This section highlights the challenges faced by nurses when dealing with the increasing number of volunteers in CHBC in Botswana. As did other healthcare systems in Africa with limited resources, Botswana initiated home-based care and

engaged volunteers to assist in caring for patients in their homes. Participants found the role of volunteers very helpful in relieving the burden on nurses. However, despite the fact that volunteers are formally recognised to work within health facilities, no clear regulatory framework oversees them. Unlike lay counsellors in South Africa and other African countries, home-based care volunteers in Botswana have no defined career path. One major concern of nurses working with volunteers was the need for incentives to encourage retention. For volunteers to view their volunteer positively and sustain their interest, there must be a balance between giving and taking (Merrell, 2000, p. 31).

In this section, four sub-themes emerged that focused on the use of volunteers and nurses' experiences with volunteers providing care to PLWAs in the community:

- Involving volunteers in the team;
- Accepting volunteers' limitations;
- Supporting volunteers;
- Advocating for volunteers.

4.5.1 Sub-theme 1: Involving volunteers in the team

Participants recognised the advantages of volunteers' involvement, and saw that their own workload, including the need to conduct home visits, was reduced by the work of volunteers:

It's just that I have volunteers who are active because they help us; it's them who visit patients most of the time. They go to the patients' home when I cannot afford to do a visit. Since I work in a 24-hour clinic sometimes I am on night duty then I have to be off duty. (Tshepo)

Nurses viewed the role of volunteers in home-based care as crucial:

I can say volunteers act as go-between the nurses, patients and families. They assist the caregivers to assess the situation and give feedback to the clinic nurse. With HIV patients you will find that they will find this particular caregiver who does not have time and will be leaving the patient unattended. When the volunteers get there they will find the patient has not been fed, and then they cook for the patient and feed the patient. (Bonno)

And: 'You know in our catchment area the volunteers are really doing a good job and they work well with the Health Education Assistants. So we rely on the feedback they give us after home visits' (Taboka).

The fact that volunteers worked locally was seen as an added advantage to the programme, as they would understand the needs of the patients and would not require transport to conduct home visits:

It is good to have volunteers in the catchment area because with those TB patients, at times they are too sick to come to the clinic to get the medications so the volunteers just go there and give them their treatment. (Lebang)

And: 'Volunteers are allocated patients around the area they live; this helps because they can walk to the patients on regular basis or as scheduled' (Tshepang).

Participants stated that some locations are hard to reach without a vehicle, and vehicles for home visits were not available:

You find that somebody is in extension nine about five kilometres... there is no-body that can walk up to there; you need a vehicle to go there. We had programme vehicles, now there are no more programme vehicles, they have

been absorbed at hospitals, of which when we ask there is no transport always, so volunteers are very important. (Bonno)

Participants indicated that volunteers were faced with high workloads and that the amount of work undertaken by volunteers was excessive, especially considering that many are older people: 'These are old people but when they get to the client's home, if there is a need to do all the household chores including making the patient comfortable, they do that' (Neo). Participants frequently stated that volunteers have increased workloads:

They do a lot of work, like here we have a patient, his relatives do not want to stay with him. So, it is the nurses and volunteers who take care of him. But the volunteers visit him most of the time. (Colleen)

And: 'During those home visits volunteers work hard... they find the PLWHAs hungry, they cook for them, feed when dirty, they bathe them and change dirty nappies' (Shirley).

Participants suggested that volunteers provide physical care above the call of duty, including household chores and other family duties: 'In some situations volunteers did prepare the patients' meals, bathed the patients and collected their drugs from the clinic or hospital' (Shirley). In addition, they provide emotional care to patients and respite services for primary caregivers: 'Volunteers offered encouragement to the patients' and families by talking to them and just listening to their problems' (Mmapula).

The participants appreciated that volunteers identified people in need of care, and encouraged them to register for a home-based care programme. Participants highlighted that by so doing, volunteers enhanced nurses' work in the community:

There are home-based care volunteers... they help us. Really, they are the ones who do most home visits and they are the ones who identify some of the clients. Maybe they will be from here or any other village. So, they know them... some of them are their relatives, neighbours, so if the neighbours identify somebody they will tell the volunteers, sometimes they identify them through consultation. (Taboka)

Participants indicated that volunteers only discovered some patients who did not go to the clinic when they were very sick. Volunteers often locate those PLWHAs who did not want to present to the clinic, and convinced them to attend: 'I find that volunteers serve an important purpose in drawing people who have slipped through the cracks of home-based care' (Bonno). And:

They are the ones identifying those clients at home who the relatives feel like not letting anyone know about... The neighbours will tell the volunteers, the volunteers will bring them to the clinic and when we get them there we find a serious problem. (Mmapula)

And: 'Volunteers report most of the patients with unmanageable symptoms and the clinic, or nurses were not aware' (Taboka).

Participants indicated that some patients and their families expected too much from the nurses and volunteers, wanting them to be there whenever they needed them: 'Some families are very difficult and demand a lot of attention. Even if we tell them that there is no transport and enough nurses to do a home visit they do not understand' (Josefa). And:

Another issue is that patients and their families expect a lot from us. I find it hard to watch family members not helping the patients but expecting volunteers, who are old women, to do all the work. This is overworking them. (Bonno)

This demand put a lot of pressure on the participants, resulting in stress. The lack of willingness of some families to participate in the care of patients was viewed as another source of stress among nurses and volunteers:

You find that some of the time, relatives just wait for the nurses or the volunteers to attend to patients' basic needs such as feeding, bathing and changing the continence aids. I try to tell the family that the patient is under their care. Nurses and volunteers will assist them during their home visits. (Lebang)

In some cases, the participants claimed that families failed to take patients to hospital for appointments with the expectation that the nurses or volunteers will do that: 'The relatives are reluctant to go to hospital and seem to expect us to take the patient. When a patient is very sick we have an ambulance, we do send them ourselves' (Lebang).

When asked if there was any solution or way to improve the situation, one participant responded: 'I don't know, maybe it would have been better for non-governmental organisations and Christian-based organisations to have greater participation in home-based care. But the government is in control of everything' (Neo).

Some participants felt that patient confidentiality issues blurred the boundaries of the contribution of volunteers in palliative care. These disputed

boundaries created conflicts among some participants with regard to patient care and confidentiality. One participant in particular felt uncomfortable with the issues of confidentiality related to the use of volunteers:

I find that another challenge is the running of the programme concerning the volunteers, you find that sometimes we face a situation where they don't maintain confidentiality, because they are not aware that they are not supposed to talk about the illness of the clients or anything we discuss about the clients. (Taboka)

This participant was concerned about the nurses' reputations in the village:

Yes, we do talk to them and let them know that what they see here is not to be discussed elsewhere because it gives us a bad name. And we tell them that if people hear that they might not want to be visited by home-based care teams. (Taboka)

Some participants felt that it was unjustified to restrict volunteers. Some participants considered nurses' restriction of volunteers' access to information about diagnoses to be unfair: 'I think we are not fair to the volunteers, we expect them to take care of patients and at the same time we do not trust that they can respect the patients' confidentiality' (Lebang). Some participants suggested that instead of feeling uncomfortable and insecure about patients' information, in their monthly meetings they should emphasise to volunteers the need for confidentiality: 'Instead of nurses feeling uncomfortable about volunteers maintaining confidentiality, the best thing is to always talk to the volunteers about these concerns' (Shirley).

Participants raised further concerns about confidentiality and volunteers. One participant observed that due to high volunteer turnover, information on confidentiality has to be constantly given as a reminder: 'I have observed that the problem is with high turnover of volunteers, every time the new ones have to be given some information on how to observe confidentiality' (Kate).

Participants' indicated that with the volunteers they sometimes found themselves dealing with family neglect. Sometimes family members said they would assist but did not take full responsibility. Participants reported how unreliable family members made the role of volunteers even more difficult:

At times some of them they do not take good care of them... at times you find people neglecting their relatives. So here I work with nurses in the clinic... I work with home-based palliative care volunteers, I also meet with relatives, the caregivers, but in some situations people will report to the clinic that people are neglecting their relative. (Pretty)

Participants explained that it was through the volunteers that they have been able to assist patients who have no caregivers. Volunteers assumed full responsibility and took over the care of such people:

You find that there is no-one looking after the patient, and whoever is available is working, which means that the CHBC volunteers should come in the morning to change the continence aids, and at times it is because there are working relatives. (Colleen)

Participants reported that in some situations, volunteers provided respite or substituted as carers of the patients:

There are situations whereby all family members are working and no-one is there to remain home with the patient. Then volunteers fill in by coming in the morning to assist with bathing, changing the continence aids. Sometimes they even cook for and feed the patient. (Colleen)

Patients who have no family members were an extra physical and emotional burden on the nurses and volunteers: 'The volunteers help him, they cook the food but it is hard during weekends, we rely on volunteers who have a good heart to help the people' (Colleen).

4.5.2 Sub-theme 2: Accepting the limitations of volunteers

The nurses suggested that the amount of work done by volunteers was possibly creating risk, as they are untrained and receive only occasional supervision: 'I am concerned about their lack of information and clinical skills; they have to be taught, for example, things like bed, bath and care to pressure area' (Colleen). And: 'I am worried about the volunteers and the quality of care, especially hands-on care, such as turning patients with no proper manual handling training or skills' (Taboka).

The participants reported that most volunteers' level of education was low, and some could not read and write: 'Their level of education is low, what I can tell, most of them cannot read or write their names. But I give those who can read books to record about patients' care activities' (Pretty).

Participants indicated that sometimes they were worried about the safety of patients as they thought the volunteers were not knowledgeable about the dosage and side-effects of drugs: 'The volunteers we have are not educated, for me this is a worry to entrust them with supervision of medications such as ARVs, but we are always busy to do the job' (Lebang). But according to the nurses, the volunteers

were passionate about what they were doing, despite their lack of skills and knowledge:

Imagine these volunteers, most of them are old women who have never been to school and have no training. But they have learnt to understand to supervise complex medications such as ARVs and also lifting very ill patients. I think it is unfair to these old people who, at times, do not even have gloves and sometimes handle secretions bare handed. (Neo)

4.5.3 Sub-theme 3: Supporting volunteers

Participants indicated that volunteers must be supported to maximise the care delivered to home-based patients: ‘volunteers must be supported because they are the ones doing most of the work’ (Mmapula). And: ‘Seeing that these people are very helpful, I do suggest that there should be nurses allocated to do a proper supervision and monitoring of what they are doing’ (Tshepo).

However, participants expressed that supervising volunteers to undertake complex tasks, including supporting them emotionally, was draining and a burden: ‘It does affect the nurses because the work they do, they need to be supported, and we really appreciate that they are doing a good job’ (Bonno). Bonno went on to say:

I say we do not support them, they will call about reporting about a situation I cannot do anything about, I am here alone at the facility, there is nothing I can do, there is no transport you see. Tomorrow they call, we do not have nappies, whatever, there is nothing I can do, it is frustrating. (Bonno)

In terms of volunteer support, the participants stressed the importance of having regular meetings:

We have a scheduled day once every month where we meet with the volunteers. So, these home-based care volunteers, they provide all the care to the client, they massage, and they do laundry and cook for them. But when they see that they can't handle it they refer the patient to the clinic or they come and report. (Mmapula)

The participants said they have learnt to employ techniques to effectively manage volunteers' stress. The need for debriefing was raised by most participants. In monthly or weekly meetings with volunteers, they have an opportunity to encourage the volunteers to give their views about clients. At these meetings participants also have an opportunity to support the volunteers in coping with their role and accepting their limitations:

It is hard to support volunteers because we are always busy. But we try to have meetings with them, and when we meet for the monthly reports we discuss the issues of their concern. At least, the volunteers are old people, they seem to like the idea that they are helping people in their village.

(Colleen)

4.5.4 Sub-theme 4: Advocating for volunteers

Most participants raised the need for more incentives: 'Volunteers are unpaid, which makes our work more difficult because I feel it will be unfair to make them do things or come to help when they do not feel like' (Lebang).

Notwithstanding the fact that home-based care volunteer work is hard due to volunteers' age and working environment, participants were upfront about the remunerations or incentives for volunteers: 'The volunteers work hard; some spend the whole day out assisting patients. The government has to improve their

remuneration' (Taboka). Participants' felt that, as volunteers were valuable in taking care of sick patients at home, their incentives should be increased:

P165.00 is very little, another challenge is when like self-help (Ipelegeng), they go there because from home-based care they are getting P165.00 at Ipelegeng, they are getting P400.00, and in home-based care they are really working, they are helping us, they check these patients, assist us, especially with the ones who do not have caregivers, they do check, they help us a lot. (Shirley)

Non-financial incentives were found to be satisfying for volunteers. For example, participants reported the need to provide umbrellas, bags and a t-shirt as a sort of uniform. One participant explained: 'Every year we give them umbrellas, shoes and bags as part of their package' (Colleen).

Working with poverty-stricken families was one of the participant's concerns. The participant was concerned about the effect that poverty among patients and their families had on the volunteers: 'Volunteers report that they get worried when they visit some of the patients, especially TB patients, and have not taken medication because they did not have any food, then they feel obliged to provide some food' (Bonno).

Volunteer work does not improve volunteers' economic situations due to inadequate incentives. They spend a lot of time doing unpaid work, and sometimes share their own resources with patients: 'It is sad because most of the volunteers are also poor but then find themselves having to provide some food for patients' (Colleen). And: 'The volunteers take care of vegetable gardens and sometimes take

these to the patients you see... yaa they really help. There are times when they even buy some food for the patients they visit' (Shirley).

Nurses indicated that due to the lack of adequate incentives it was hard to sustain a pool of volunteers. It was particularly difficult to attract and retain younger, more literate volunteers:

Some have just decided that they are leaving it, because they volunteered, they are not given anything because even though they get P165.00 it is very small... they said it was transport allowance. You find that somebody has to go there voluntarily to assist that particular patient leaving her kids, leaving everything that she could do and then at the end of the day to get only P165.00 a month. (Bonno)

The nurses found that it was hard to attract young volunteers:

The problem is that our volunteers, only those old-age people, are the ones volunteering, as for the youth, because they are looking at the income and say, I cannot depend on P165.00 (\$25.00) to volunteer just like that, I cannot do it. However, these people of god, the volunteers are doing a good job. (Bonno)

4.5.5 Conclusion

Within this study, the lack of leadership at management level emerged as a key factor that affected the performance of home-based care, and magnified the chaos in which nurses worked. Nurses questioned management's credibility in fostering both goals and resource mobilisation. Despite the fact that district managers were involved in the change process, the nurses felt that management's perception of

what was a fair distribution of staff between clinics and hospitals was skewed by a sense of loyalty to the hospitals.

Due to perceived inadequacies in management, nurses felt that they lacked direction. Many managers were just transferred from hospitals without any prior orientation to, or experience in, managing districts. The managers themselves said that the MoH failed to support them. This undermined their ability to manage effectively, and had implications for the implementation of programmes.

The changes in the delivery of home-based palliative care services following the introduction of centralised, government-controlled health services caused a severe disconnect between nurses and management. This study demonstrates that making better use of nurses in decision-making during the change process is essential. Making better use of nursing skills and knowledge is also pivotal to improving the delivery of CHBC. However, the contribution that could have been made by the largest group of health professionals in the health delivery system was overlooked and overshadowed by the participation of the nurses' managers.

In this study, the complexity of providing palliative CHBC was acknowledged, as was its impact on the nurses. The new demands associated with working in CHBC are tainted by a lack of enjoyment of the job. While nurses value working with patients, their work environment is dissatisfying. Staff shortages, multitasking and excessive workloads were identified as some of the factors that led to unhappiness in the job.

During relocation, efficiency and effectiveness of service delivery was hampered by poor coordination of services. The functioning of inter-professional teams, which made a significant contribution to the provision of care to patients at

home, was disrupted. In strengthening home-based care, there was a need for the MoH to ensure alignment and coherence of policies and priorities among different home-based care stakeholders. The findings suggest that successful implementation of home-based care requires cross-disciplinary collaboration with good coordination of services.

This study concludes that nurses feel that the relocation of services within the healthcare delivery system was poorly prepared and has thus resulted in chaos. They described the healthcare system as ‘failing them’ and making it difficult for them to provide palliative CHBC for PLWHAs and their families. The wide community participation in PHC and, specifically, the experience of volunteers in CHBC in Botswana have been acknowledged as important components in the provision of community-based palliative care. Training of community volunteers emerged as a key factor in ensuring that the provision of care is convenient and accessible to all patients needing community palliative care. However, challenges lie in the availability of resources from, and the organisation mandated by, the MoH.

The emotional demands associated with home-based care and in particular, the impact on volunteers while providing care was revealed. Supervision and other forms of support, such as supplies and clinical supervision, were acknowledged as crucial for continued quality care at home. Only good supervision, adequate material support and training will enable volunteers to function safely. While nurses valued working with volunteers in home-based care, their working conditions remain unsatisfactory, resulting in stress for the nurses. Of most significance to this study was that nurses perceived elderly volunteers to be more positive than younger ones. Bias against the emotional capacity of volunteers was clearly shared by most nurses.

This bias needs to be dealt with to improve the retention of volunteers in home-based care.

The participants suggested that volunteers were provided with less information than they should have been because medical staff did not find it necessary, particularly considering concerns over protecting patient confidentiality. The results also suggest that nurses underestimate the level at which volunteers can securely maintain patients' information. Lack of professional or in-depth training should not be determining factors in denying volunteers information regarding patients' diagnoses, since these volunteers are handling and managing patients daily. Such limited dissemination of information results in more inadequacies and inefficiency in patient care, which may compromise both the volunteers and patients.

The participants were also frustrated by the fact that volunteers, who are also poor, were not equipped to address the overwhelming problems of poverty among home-based care patients. Participants' perceptions were that volunteers were overwhelmed at times by the high expectations of families. Motivation to help volunteers and ensure that the best care was provided remained an issue. Strengthening volunteers' motivation and addressing their concerns is crucial to providing effective home care. Home-based care volunteers receive small stipends and material items such as t-shirts and umbrellas, but this is not sufficient remuneration for the work they do.

The next chapter provides an overview and discussion of the findings, outlines recommendations for education, practice and research, and addresses the limitations of this study.

Chapter 5: Discussion

This study was undertaken to explore the experiences of nurses providing home-based palliative care to PLWHAs in Botswana. Findings from this study have confirmed the results of previous studies on the burden suffered by nurses while providing palliative care particularly in resource constrained settings. However, by documenting nurses' experiences it provides a valuable contribution to home based palliative care nursing in Botswana. These findings suggest that the culture in which nurses were operating influenced their experiences and individual attitudes towards motivation, satisfaction, morale and power. Nurses in Botswana comprise the largest proportion of health care providers (Nkomazana et al., 2015), and globally are at the frontline of health care provision, are well placed to raise concerns about quality care and patient safety (Jackson et al., 2014, p.240). If the work environment is not improved the consequences could be dire for home-based care patients. Analysis of the data obtained revealed four themes. This chapter discusses the struggles home based care nurses encountered while caring for the patients in their homes and the gaps in executing their advocacy role.

The themes revealed that nurses delivering community based palliative care were:

- Working in chaos;
- Struggling for advocacy;
- Dealing with HIV/AIDS stigma and discrimination;
- Committed to supporting volunteers.

The major themes are examined in detail in this chapter.

5.1 Theme 1: Nurses Working in Chaos

As nurses recounted their lived experiences of delivering home-based care, reports of chaotic incidents emerged. Nursing practice involves complex dynamic systems (Haigh, 2008), and the use of the descriptor 'chaos' is relevant to this experience. According to Haigh (2008), chaos theory explains that as nursing becomes more complex; practitioners need to become familiar with change and the potential for chaos. In this context, chaos is not simple anarchy but a complex system that follows rules (Gleick, 1987).

According to Duffy, chaos theory explains periods in which change occurs in an unpredictable, irregular and uncertain ways (Duffy, 2000, p.234). Applying chaos theory to organisational behaviour assumes that a system creates its own order (Haigh, 2008; Pryor et al., 2008), must be self-organising (Wheatley, 2006), and must be ready to adapt to change in order to survive (Yoder-Wise, 2013). One of the underlying principles in chaos theory is that order emerges out of chaos and that everything is interrelated (Haigh, 2008; Pryor et al., 2008). How employees within organisations deal with change varies depending on the organisational culture and the approach taken by management.

The relocation of PHC services from the MLG to the MoH in 2010 created a chaotic environment for Botswana CHBC nurses. Rhéaume et al. maintained that chaos in the workplace may be a function of a system re-organising itself gradually (Rhéaume et al., 2007). Conversely, it may be a function of a badly conceived, poorly executed attempt of top-down organisational change (Alshammari et al., 2016; Wheatley, 2006). The most basic test for understanding the type of chaos found in Botswana is an evaluation of whether the chaos produced progress and

advanced the adaptation of the change. From the perspectives of participants in this study, the Botswana reorganisation did not. The descriptions provided by participants regarding relocation indicated that nurses were stressed by attempting to deliver quality care within the reorganised work environment. The loss of the previous structure, in which all districts had home based care coordinators and vehicles assigned to the programme, influenced how nurses perceived the delivery of home based care. The removal of vehicles and coordinators indicated that home based care was being given less priority compared to other programmes.

Chaos theory indicates that where there is instability in a system it can “never return to the exact same state” (Levy, 1994, p. 168). However, Adcroft and Mason argued that when negative feedback or bad influences within an organisation are dealt with effectively the organisation can approach its original state resulting in stability (Adcroft & Mason, 2007). According to proponents of chaos theory, organisational change where there is no stability can affect performance (Wheatley, 2006). In this study the disruption that occurred during relocation controlled and affected the continuity of patients’ care. The effects of organisational change in such a fluid situation can be severe (Gleick, 1987). For nurses to function better in Botswana the study suggested that even with this unpredictable system the home-based nurses required stability to operate effectively. To combat this instability there was a need to manage uncertainty and give the nurses genuine power within the home-based care structure.

According to Wheatley (2006), slight changes that may not seem obvious have a potential to bring unexpected results, which may blow out into chaos. In order to take advantage and deal with the chaos, the findings of this study suggest that the

health services managers needed to try to manage organisational patterns that may lead to certain positive types of behaviour within the relocation process. In this context of change it was apparent that the health managers failed to acknowledge the complexities associated with transformation of an organisational environment already pre-disposed to chaos. Mitchell maintained that without this acknowledgement, the change process may fail (Mitchell, 2013). Finally, Wheatley (2006) observed that chaos is the final situation in a system that has reached turbulence and lacks direction and or order. Findings from this study support the arguments by Mitchell and Wheatley and acknowledge the need for adequate support for nurses in the context of health change.

5.1.1 Lack of engagement of practising nurses

Implementing sustainable and meaningful change means supporting the employees in dealing with the change (Wellman et al., 2016). Change can undermine confidence and threaten employees' sense of purpose (Holbeche, 2006). In creating comprehensive health reform strategies, it is important to develop a culture that supports nurses' involvement, because change is not an event but a process (Connolly et al., 2015). For the Botswana health system management to avoid this dysfunction it was essential to prepare staff for the change.

Effective change requires a progression through a series of phases, each one needing time to stabilise (Bridges, 2009), and skipping stages will not yield the anticipated outcomes. Lewin first identified three stages of organisational change: unfreezing (when change is needed), moving (when change is initiated) and refreezing (when equilibrium is established) (Lewin, 1951). For Lewin, the process of change entailed first creating the perception that a change is needed, then moving

toward the new desired pattern of behaviour. Lewin suggested that by increasing effective forces and reducing restraining influences, the system can move to a point of stability, increasing positive attributes for change while lessening the restraining forces (McShane & Von Glinow, 2005). Lippitt et al. refined Lewin's stages into seven phases: diagnosing the problem, assessing motivation and capacity for change, assessing change agents' motivation and resources, selecting progressive change objective, choosing the appropriate role of the change agent, maintaining the change and terminating the helping relationship (Lippitt et al., 1958), while Rogers envisaged the stages as awareness, interest and evaluation, trial and adoption (Rogers, 1983).

The process affecting the nurses in this study featured classic management mistakes, similar to those described in Rogers' example of failed diffusion of innovation in Peru (Rogers, 1983, p.3). In the Peru case the innovation was rejected because no attempt was made to integrate the new process into the existing structure. Similarly, participants in the current study reported a lack of confidence in the new structure, and had abandoned expectations about job security, control, stability and becoming comfortable with chaos. During the consultative process in Botswana, some DHT managers and other matrons were transferred, resulting in a skills shortage. In the context of this study the perception was that newly appointed managers were often uninformed about the needs of the CHBC nurses. Furthermore, the nurses delivering the services to patients and families were not well-informed about the change process itself.

Organisational change can be unnerving and staff tend to resist letting go of familiar practices (Bridges, 2009), as was evidenced by participants' comments in

the current study. There appeared to be pre-existing confusion and fragmentation in the Botswana health care system, amid this chaos participating nurses were stressed about the fragmentation of home based programme. Further increasing the nurses' stress was the instability and uncertainty that came with change when nurses were not prepared for it. During organisational change values and employee expectations are disrupted (Arbuckle, 2012). The lack of consistency in home visits and other irregularities they observed in their work environment contributed to the participants' apathy, and as a result were no longer sure of their role.

Tetenbaum and Laurence observed that intended organisational change and stability rely on the cooperation of employees (Tetenbaum & Laurence, 2011). When managing change, it is important for change agents to identify with employees to reduce the possible resistance, because improved interpersonal relations have the potential to increase trust (Rolfe, 2011) and leaders' credibility (Jackson & Daly, 2011). When nurses understand the need for change they are often willing to participate (Schmalenberg & Kramer, 2008). Without support, nurses were predisposed to resist the changes, even though the change might be to their ultimate benefit. In practice, most changes fail because nurses are not supported and empowered to adjust to new ways of working (Holbeche, 2006; Tetenbaum & Laurence, 2011). When change is the incitement to chaos, giving employees ample time to function through the change and learn the ways to adapt and develop as a team can be difficult (Otten & Chen, 2011). However, in this scenario nurses were concerned that the instability had prevailed for more than a year. The instabilities and the chaos were made worse by caring for patients who were in their homes with limited resources and support.

The element mentioned by participants that negatively influenced their views was their lack of involvement in planning. Participating nurses did not consider themselves as partners; instead the relocation process was an imposed undertaking. This lack of engagement led to a perception of the loss of autonomy, and contributed to a level of nurse passivity and feelings of helplessness. Feelings of being undervalued created a context in which nurses stopped trying so hard, and they subsequently exhibited a level of dependence on the health managers to redirect the home-based care programme. The demoralisation that resulted caused nurses, unable to fulfil their professional obligations, to emotionally detach themselves from their work

5.1.2 Inadequate communication of process

In every organisation communication is the driving force for effective teamwork (Chadwick, 2010), and is essential to knowledge transmission (Spiers et al., 2016). Participants in this study not only reported less safe workplace conditions, but felt the chaos resulting from the changes was on-going, with poor communication creating further barriers. When levels of leadership fail to disclose information or adequately communicate throughout the levels, an environment of uncertainty and frustration can be created, which tend to ripple down to the frontline staff, negatively affecting the work environment (Spiers et al., 2016, p.79). In this study, it was apparent that inadequate communication about the change influenced how the practicing nurses embraced the change. The nurses' perception about the success of the relocation was prejudiced by the lack of trust in the management to effectively manage the change. Regrettably, participating nurses lacked the confidence to express their thoughts, and failed to communicate their concerns

adequately. In addition, they did not manage to set aside their judgement or withhold blame and criticism in order to understand the new structure.

Good communication is a prominent feature to implement effective change process (Levinson et al., 2010; Mitchell, 2013), producing positive outcomes such as patient safety and employee satisfaction (Farhadi et al., 2016). If change is to be effective it must be developed in partnership with staff. In the current study participant narratives revealed that inadequate communication and collaboration resulted in nurses feeling uninvolved in patient care decision-making. Effective communication improves coordination, horizontal communication and teamwork (Levinson et al., 2010). Information and imparting of knowledge succeed better when interaction and collaboration are uninterrupted (Farhadi et al., 2016; Klein & Hopper, 2013; Tetenbaum & Laurence, 2011). What was required in the Botswana situation was transparency about the new innovations. Nurses wanted to feel informed, secure, and comfortable and trusting of those perceived as implementing the change. However, obtaining the trust of workers may be most difficult in times of change, which is the time when it is needed most (Marquis & Huston, 2009; Tetenbaum & Laurence, 2011). When communication lines are open, even negative or difficult messages can be conveyed without creating conflict or destroying trust (Levinson et al., 2010), because effective communication helps deepen connections to improve teamwork, decision making and problem solving (Klein & Hopper, 2013).

For chaos inspired change to occur effectively, nurses need a good understanding of the context and purpose of health reforms (Anazor, 2012), strength and confidence to be proactive and fully involved in the stressful and challenging

change processes (Otten & Chen, 2011). The findings from this study suggest that throughout the disruption, there was no evidence of a growing stability in communication or the development of the necessary flexibility in leadership to call it a system in the process of 'chaotic' growth. The environment in which the nurses operated in was plagued by disorder and difficulties in the provision of care. The challenge was that there seemed to be ever-mounting confusion among the nurses, due to a lack of proper communication, which resulted in increasing job dissatisfaction and a corrosive lack of confidence in themselves as professionals.

5.1.3 Out of context Management

A challenging work environment, which can be complicated by inefficient leadership and inadequate support to local managers, has been associated with reduction in the quality of care nurses provide (Boev, 2012; Laschinger et al., 2009). Management has an important role throughout the change process (Chadwick, 2010) and a key obligation to maintain the organisational coherence (Hodson et al., 2006). Roscigno et al. caution that organisational chaos is not the opposite or absence of bureaucracy, rather it can emerge in highly bureaucratic organisations when formal rules or procedures do not ensure a well-coordinated process (Roscigno et al., 2009, p.749). This result highlight that management did not make predictions or apply any knowledge regarding the impact of change and inevitable chaos.

Given the perceived redeployment of managers to areas where they had no expertise it is not surprising that both the nurses and the new managers felt overwhelmed and unsupported. Eventually participating nurses felt disempowered in fulfilling their nursing obligations. Botswana health care system needed to improve both employees' and management's understanding of changes and increased their

level of discretion and autonomy regarding the change. According to Anazor and Chadwick, for organisations to have effective leadership, managers need to be knowledgeable and prepared for an expanded role (Anazor, 2012; Chadwick, 2010).

Roscigno et al. observed that organisational chaos leads to loss of managerial control over employees (Roscigno et al., 2009). Nursing leaders are able to guide and mentor practising nurses (Anonson et al., 2014), therefore leadership education was fundamental to the change process for leadership to remain in control. However, in this study the perceived management lack of experience and lack of knowledge about community work were associated with the exacerbation of chaos that prevailed in home based care. The conclusion was drawn by this study's participants, that the new managers were struggling to effectively execute their roles. The unique challenge as observed in this study was for managers to support nurses in providing quality care outside the clinical environment where most had no prior experience. Furthermore, Doody & Doody observed that for best results, nurse leaders need to be brought on as mentors and role models for their staff by management (Doody & Doody, 2012).

Health leaders are change agents who can create cohesion and influence organisational culture through their leadership practices (Lanzoni et al., 2016). The study participants perceived that if the value of nursing leadership in home based care was given the prominence it deserved and was properly supported, they would have been able to achieve better patient care outcomes. Anonson et al. argued that healthcare organisations need to broaden the roles of leadership to include multi-level support for nurses in the field (Anonson et al., 2014). The nursing literature suggests that working without proper inclusive team planning and the lack of

managerial support is counterproductive (Lanzoni et al., 2016). Health system management should develop innovative responses to the realities of the change relocation process, but the perception was that health managers were faced with challenges because of their limited knowledge of palliative care and community work, which compromised patient care.

It has been observed that practicing nurses are often not involved in planning for quality patient care measures. For example, nurse managers, educators and researchers who engage in the planning process are, in most cases, not in practising roles (Burhans & Alligood, 2010). Participation and inclusion in decision making offer an increased understanding of circumstances that make change necessary, and a sense of ownership (Anazor, 2012). This sense ownership was lacking for new managers as well as the CHBC nurses.

5.1.4 Poor coordination

Coordination is crucial for the effectiveness of home based care and during the study period participants indicated that as a result of the chaos, there was no meaningful coordination of the CHBC programmes. Uwimana et al. observed that in South Africa at community level programmes were being run vertically. Where these services are provided there is no integration of services and each NGO focuses on a particular disease (Uwimana et al., 2012, p.658). Similarly, this study highlighted that there was fragmentation of services: for example, the TB and HIV programme had its own staff and vehicles which were not shared with the CHBC and palliative care programmes.

The PHC sector has a major role in coordinating care and this has increased as more care is provided in the community (Davies et al., 2008). Multidisciplinary

and collaborative approaches are important elements to improve the coordination of services at community level (World Health Organization, 2002). The lack of coordination and collaboration between services was of concern to the participants because partnerships with key stakeholders such as Community and Social Development were compromised, and information sharing about the patients was disjointed. In the previous structure, each stakeholder had his/her role clearly defined; nurses and social workers identified themselves as partners of the multidisciplinary team focusing on patient care outcomes.

Persons with complex needs such as PLWHAs and those on palliative care need continuous management (Lowther et al., 2012), and consistent effort from different professionals (Mwai et al., 2013), which the study participants perceived was lacking in this situation. It appears during the relocation planning there was less consideration of maintaining or improving coordination of care through PHC. This lack of coordination and collaboration modalities further created confusion and chaos in the delivery of care to patients in the community. The disruption of the previous multidisciplinary approach further contributed to the chaos.

Redeployment and retrenchment predispose employees to stress and uncertainties (Jimmieson et al., 2004). This finding is similar to those of Donnelly, who found that that redeployment to work in different settings is evidently a major stress for nurses (Donnelly, 2014). In addition, Donnelly (2014) observed that even though redeployment in other areas was the main stressor for the nurses, it was not adequately addressed. Jackson et al. observed that in these unpredictable and work environments employees are expected to continue their jobs regardless of the chaos (Jackson et al., 1987). During this process, nurses were often transferred into new

health settings (i.e., hospital nurses transferred to community clinics). These results provide evidence of nurses' lack of control of their home-based care responsibilities while being transferred from one clinic to another. The reality of the situation as perceived by participating nurses was that these regular transfers created chaos and contributed to the poor coordination of home based care services, effectively compromising patient care.

Nurses gain more experience and increase their confidence as they gain more exposure in their area of work (Barchi et al., 2014). In the current study, connections with patients and families were constrained by transfers, resulting in nurses failing to effectively coordinate their work and that done by volunteers. Due to these frequent transfers nurses had no time to acquire knowledge of the community and put together long-term, home-based care plans. The transfers were perceived as chaotic and distressing. As the chaos continued, nurses lost interest and motivation and their energy and enthusiasm towards work was reduced. Participant nurses felt increasingly helpless, hopeless, cynical and resentful towards home-based care work. They eventually felt that they had nothing to offer amid the chaos.

5.1.5 Lack of enjoyment

Jackson et al. posited that relentless human suffering and distress of patients characterise the nature of nursing, which is a source of stress (Jackson et al., 2007). Caring for people is challenging, and nurses face ethical dilemmas and issues that may cause moral distress (Turale, 2014). The study identified that participating nurses were undergoing immense stress and their sense of doing good was affected by lack of resources and poor support. Borglin argued that even with the availability of advanced interventions, HIV/AIDS, cancer and other conditions have frequently

been identified as distressing (Borglin et al., 2011). Participating nurses suggested they were frustrated with neglecting their role in home based care and being overworked at the clinic. The vulnerability that comes with being a home-based care nurse in a non-supportive environment which was plagued by chaos could not be underestimated. This caused what authors in nursing and advocacy literature have described as moral distress. Moral distress stems from an act in which nurses knowingly failed to act in the best interest of patients under their care (Barlem et al., 2012; Brazil et al., 2010; Fournier et al., 2007; Harrowing & Mill, 2010; Pereira et al., 2011; Piers et al., 2012). The negative consequences of their failure to provide adequate patient care were expressed not only as feelings of guilt, but also as conflicts leading to lack of enjoyment of their job. In such a chaotic work environment, nurses can end up feeling powerless and unable to do the right thing (Bu & Jezewski, 2007).

Lamb and Storch argued that moral distress in nursing seems entrenched in the longstanding failure to acknowledge the moral complexity of nursing (Lamb & Storch, 2012). The participants in this study observed that the difficult working environment and the fact that they were not questioning practices that were problematic to patient care were stressful. Nurses participating in this study were constrained in speaking on behalf of patients and harboured intense emotional feelings.

Less preparation for the nurses and lack of time to deliver care have been found to have a profound effect on moral suffering among nurses (Barlem et al., 2012). The occurrence of nurses' stress in this study is similar to that expressed in other studies; however in this context the lack of material and human resources and

nurses' powerlessness to support patient safety increased the nurses' vulnerability to stress. It is noteworthy that the working environment was a constant challenge for these nurses, who found it difficult to work closely with patients and families. Barchi et al. argued that uncertainty could have a potentially positive outcome that could stimulate the employees or even be the catalyst for change (Barchi et al., 2014). New and difficult work situations could possibly improve a nurse's proficiency and promote resilience (Jackson et al., 2007). In this case I think the uncertainty has had a considerably adverse influence on the work environment and exacerbated employees' responses.

5.1.6 Conclusion

Although nurses had strong commitment to deliver home based care, the re-organisation produced nurse de-motivation. The Botswana implementation strategy did not produce a change process characterised by control and predictability. The current organisational structure, resources and skills could barely accommodate the proposed changes, which adversely affected the quality of health care and increased the chaos. Health sector performance is critically dependent on worker motivation, with service quality, efficiency and equity depending upon it (Chadwick, 2010). Participants reported that nurses had a professional obligation to provide high-quality care to home-based patients, regardless of the chaos. However, they felt vulnerable and helpless because they did not have the capacity to control and manage the change. They succumbed to the tensions placed on them by the mismatch between their personal obligations and organisational values, and felt there was a lack of recognition of their professional obligation to provide optimal patient

care. Clearly, these factors have on-going implications for nurses' work, work that is often regarded as unattractive and difficult.

5.2 Theme 2: Nurses Struggling for Advocacy

5.2.1 Introduction

“Never underestimate the power and influence that you have on the health environment. Paying attention to small things is as important as a major renovation” (May & Mion, 2013, p.74).

Managing physical symptoms, providing emotional support and discussing day to day living are important for patients with terminal illnesses (Salins et al., 2016; Vaartio-Rajalin & Leino-Kilpi, 2011; Vaartio et al., 2006). However, studies have confirmed that nurses become stressed and display negative attitudes due to the type of work involved and may fail to advocate adequately for patients while under stress (MacDonald, 2007; McSteen & Peden-McAlpine, 2006). Cultures of safety promote and encourage staff to raise issues of concern (Jackson & Daly, 2011; Jackson et al., 2014), yet most workplace cultures are imperfect and nurses may face challenges in their advocacy efforts (Zolnierek & Clingerman, 2012). Furthermore, organisational restructuring, excessive workloads and nurses' lack of autonomy are also related to nurses experiencing negative workplace related challenges (Jackson et al., 2007).

Reflecting on nurses' failure to advocate on behalf of patients further raises potential ethical implications (Jackson et al., 2014). In history, professional nurses were judged on how well they executed the orders of doctors (Kalisch & Kalisch, 1977; Keddy et al., 1986). Doctors trained nurses and their recommendations determined who was employed. Nurses had to be clever and careful to have their recommendations on patient care acted upon; they often had to resort to playing 'the

doctor-nurse game' (Stein, 1967), which promoted the inclusion of nurse ideas into the doctors' treatments as the doctors' own ideas. Even though advocacy for patients is part of the nurses' role, nurses struggle to speak on behalf of patients, especially when there is uncertainty in decision making (Bu & Jezewski, 2007; Jackson et al., 2014; Mallik, 1997; Tariman et al., 2016; Vaartio et al., 2006).

Before the 1970s, 'there was very little demand for patients' rights' (Mallik, 1997). However, in the Western world, a new emphasis on patients' rights began to change the dynamic between nurses and doctors during the 1970s (Annas, 1974). Curtin, Gadow and Kohnke developed the definition of this new role, with emphasis on patients' right to self-determination and autonomy (Curtin, 1979; Gadow, 1980; Kohnke, 1980). By 1976, the US Code for Professional Nurses had been revised to include an emphasis on autonomy in nursing and the promotion of nursing advocacy (Fowler, 2008, p. xvi). Advocacy in nursing involves intervening on behalf of a patient in situations with ethical dilemmas (Gazarian et al., 2016; Vaartio & Leino-Kilpi, 2005). Bu and Jezewski identified three core attributes of nursing advocacy: safeguarding patient autonomy, acting on behalf of patients and promoting social justice (Bu & Jezewski, 2007). These are considered to be essential component of palliative and end of life care (Thacker, 2008). Part of the role of nurse advocate involves speaking out for patients (Hanks, 2008).

Nurses in home based care also need to inform patients and families about aspects of their care, in order to ensure that they have adequate information on which to act. An ethical dilemma exists for the nurses as advocates when some evidence indicates that an act is morally right and some evidence indicated that the same act is morally wrong (Monterosso et al., 2005, p.109). In dealing with PLWHAs' in their

homes, nurses had to deal with the patients and their families' vulnerability and associated stigma. In this respect nurses felt they had an obligation to care and be sensitive to the patients physical and emotional as well as respect their wishes in their home environment. The creation of an emotional connection between nurses and their patients' and the act of developing meaningful understanding are important attributes of advocacy (MacDonald, 2007). This study has shown that the relationship with patients and families was compromised by lack of adequate home visits. In studying the comments from the participants' narratives, it became obvious that the nurses were struggling to perform what they felt was a significant part of their role in home based care: patient advocacy. The role obviously had importance for them, and to neglect it caused them discomfort. The role of patient advocacy in home based patient care, therefore, required further examination.

Palliative care in Botswana is a relatively new concept which has been introduced into home based care (Mudanga et al., 2008), bringing with it conflicting themes between cultural and modern health care beliefs. Nurses have been taught that patient advocacy is a fundamental part of their role (Bu & Jezewski, 2007; MacDonald, 2007; Mallik, 1997; Vaartio et al., 2006), but their work environment was often not receptive to its operations. Not only did the nurses have difficulties in dealing with doctors on an equal basis, but the concept of palliative care itself was not well developed in Africa (Gysels et al., 2011).

Ama argued that community home based care in Botswana is entrenched in the belief of maintaining traditional caring patterns whereby families take responsibility of the sick family member (Ama, 2011). However, HIV/AIDS has challenged the traditional caring structures, as discussed earlier in this thesis. Some

families may not be willing to care for sick PLWHAs or may not be available to do so. Family caring for PLWHA and other chronic ill patients is often a challenge (Kang'ethe, 2009). This study established that Botswana is experiencing an increase in the number of chronically ill patients needing palliative care at home, but have no caregivers or family to provide the care. The participants found this emerging trend disturbing. The AIDS epidemic has caused adverse psychosocial consequences, leading to changes in family structure and disturbing the capacity of extended families to respond to the needs of the affected family members. Hence, in addition to daily care of patients the unavailability of primary care givers or extended families increased the burden on the nurses. It is worth noting that despite the input of nurses and volunteers, care in the home relies on the support of family, and nurses found that without the support of family members or primary caregivers the job was hard. This might mean that these patients might not have access to care, causing a dilemma for nurses, since they felt had a duty of care and professional obligations. The underlying assumption is that there was a conflict between nursing practice and caring for vulnerable patients outside the formal health care setting.

5.2.2 Perceived lack of power

Nurses' advocacy relationship with doctors involves nurses negotiating with both doctors and the healthcare hierarchy on behalf of patients (Pullon, 2008; Stein, 1967). Ideally, nurses mediate between doctors, patients and their families (Tabak & Orit, 2007), assisting patients in making choices and discussing options with family and doctors (Farhadi et al., 2016). Benner stressed that teamwork and collaboration between health professionals and different disciplines were crucial for the best interest of patients (Benner, 1984). However, in the current study the workplace

power relations challenged nurses in executing their role, as the collaboration between nurses and doctors was not perceived as collegial and did not facilitate a place to operate at equal power with professional respect.

Nursing advocacy in palliative care encompasses pain and symptom management, ethical decision making, culturally sensitive nursing care and caring for patients through the process of death and dying (Pullis, 2013, p. 464). Nurses use their role to promote and safeguard the wellbeing and interests of patients (Vaartio-Rajalin & Leino-Kilpi, 2011) and play a pivotal role as informed advocates throughout the disease trajectory for many chronically and terminally ill patients at home. Patients in pain are a vulnerable group who often need nurses to advocate on their behalf for the best possible pain management (Ware et al., 2011). Despite the shortage of human resource of doctors and nurses in Botswana, the study established that only medical doctors were allowed to prescribe strong pain medication (opioids). Furthermore, this study result suggests that, when nurses feel ignored when trying to act in the best interest of patients, they frequently experienced feelings of powerlessness. This illustrates the emotional response of nurse experienced by nurses when dealing with unsuccessful attempts to advocate for patients' analgesia (MacDonald, 2007).

Historically, in Botswana, due to shortage of doctors in primary health care facilities, nurses have traditionally had consultation and prescription rights (Boonstra et al., 2002). In addition, the Drugs and Related Substance Act 1992 granted legal authority to Registered Nurses to prescribe specific drugs from Botswana National Drug Formulary and to adhere to guidelines (Botswana, 1992). However, in resource constrained situations medicine can be scarce, and participants indicated that aspirin,

paracetamol and indomethacin were often unavailable and sometimes not given in adequate doses to relieve the pain. Furthermore, in the context of this study, a lack of knowledge and a lack of or inadequacy of appropriate pain relief analgesics hampered the nurses in executing their role. For Botswana nurses to effectively advocate for patients care and provide access to strong analgesics in the community, the health system needs to adequately prepare the nurses for the role and provide adequate amounts of opioids in the community.

The authoritative position given to doctors in decision making on patient care, as perceived by participants, was significant in this study. Nurses in Botswana have been trained to prescribe ARV where there are no doctors (Monyatsi et al., 2012; Van Lerberghe & World Health Organization, 2008). Therefore, this study would suggest that this situation could be viewed as an opportunity for health managers to fast track the approval for nurses to prescribe opioids, particularly in those in remote areas where there are no doctors or pharmacists. In her study on critical care nurses and moral distress, Gutierrez reported that participants in her study found it difficult to reason with the medical decision makers and advocate for patients about analgesics, even after voicing their concerns to the charge nurse (Gutierrez, 2005). Similarly, participating nurses felt inhibited by doctors' dominance and their failure to prescribe appropriate analgesics. Participating nurses felt oppressed by the hierarchy and bureaucracy: they lacked confidence, undervalued their role and eventually became disengaged, which affected their ability to be proactive in speaking on behalf of the patients. They experienced the same forces of a social system that devalues patient autonomy and restricts access to

healthcare services. Nurses in this study carried responsibility without the authority to fulfil that responsibility or to challenge decisions.

The literature has focused on the interaction between doctors and nurses and has identified nurses' passivity and their lack of confidence about asserting themselves in the discussions (Falana et al., 2016; Farhadi et al., 2016). Similarly, the participants in the current study suggested that they faced resistance from some doctors when they were not fully equipped to deal with the home-based care dynamics. Facilitated by a lack of understanding and mostly poor communication (Falana et al., 2016; Pun et al., 2015), conflict between the two professions is bound to occur (Slade et al., 2015), unless there is an intervention to prevent it. Falana et al. concluded that collaboration between doctors and nurses is still a major challenge for health administration and the political sphere (Falana et al., 2016).

Even though doctors and nurses agree that their priority is better outcomes in patient care (Falana et al., 2016), participants acknowledged that home based care services continued to position palliative care patients who rely on health professional expertise at a disadvantage because of their poor advocacy skills. As such, organisational disputes are likely impede the efficacy of care (Falana et al., 2016). Without clarifying interactions between doctors and nurses in Botswana, nurses have no starting point from which to challenge the status quo. This impasse could have serious implications for home based care patients, especially those who need immediate medical attention.

Although the prevalence of pain is high throughout the trajectory of the HIV/AIDS disease, PLWHAs on home based care particularly, have gone without adequate pain and symptom control (Connor & Sepulveda Bermedo, 2014).

Adequate pain relief improves the quality of life so that patients can participate in their daily living activities (Tse & Ho, 2014). This study shows that the failure to relieve severe pain and other distressing symptoms had negative effects and produced intense psychological suffering for the nurses. The role of nurses is important in the assessment and management of pain (Francis & Fitzpatrick, 2013).

In analysing the advocacy role, several authors have recognised that nurses acting as advocates have been labelled as troublemakers (Zomorodi & Foley, 2009), have been accused of being insubordinate and have suffered loss of reputation (Mahlin, 2010; Olin, 2012; Vaartio et al., 2006), and risked being alienated (Hanks, 2008, 2010). These results are also reflected in the study by Choi et al. who observed that nurses are exposed to workplace victimisation while practising their advocacy role (Choi et al., 2014). Similarly, participants in this study felt that speaking for the best interest of patients would expose them to victimisation, and they feared retribution and possible transfer to a location not of their preference. Jackson et al. stated that “nursing plays a key role in maintaining practice standards and in reporting care that is unacceptable although the repercussions to nurses who raise concerns are insupportable (Jackson et al., 2014, p.240).

The resulting powerlessness correlates with moral distress, defined by Jameton (1984) as the feeling that results from a situation in which one knows the right action to take, but is constrained from taking it. This phenomenon has been of concern to the profession since that time (Barlem et al., 2012; Carnevale, 2013; Gallagher, 2011; Jameton, 1984; Jurchak & Pennington, 2009). In this study, even though participating nurses were unable to deliver adequate care to home based palliative patients, they were acutely aware of the needs of those in their care. In

such distressing moral situations, unsuccessful attempts to advocate for patients intensified the stress. Barlem et al. concluded that the greatest perception of moral distress was associated with lack of competence, followed by denial of the nurses' authority (Barlem et al., 2012). Similarly, the results of this study show that the ongoing failure to achieve good patient care outcomes by confronting management made nurses experience strong feelings of anger and frustration. Failure to conduct home visits and assess very sick patients in the community was also associated with feelings of frustration and helplessness.

5.2.3 Perceived Lack of Knowledge

Gaps in advocacy provision identified in this study were attributed to a lack of the palliative care knowledge which would allow nurses to effectively advocate for patients with complex needs in their homes. A higher level of education and training has been linked with successful advocacy (Hanks, 2010; Virani et al., 2014), and assists in minimising the communication problems between the patients and health care providers (Gazarian et al., 2016). Gysels et al. (2011), maintained that health workers in Sub Saharan Africa lacked palliative care knowledge, while Powell and Hunt (2013) doubted whether the quality of training provided could equip nurses to provide quality palliative care. This study suggests that the lack of adequate training to provide palliative care inhibited nurses in their advocacy role. The literature suggests that increased nurses' levels of education is associated with perceived autonomy and increased likelihood of advocating for patients (Gazarian et al., 2016; Hanks, 2010). Without training on palliative care, participating nurses felt they lacked power in care situations to advocate for pain relief for patients suffering severe pain, particularly at the end of life.

It is noted that the skills required to provide effective palliative and pain management strategies are not adequately acquired during nursing training (Tse & Ho, 2014). Lack of knowledge and experience in palliative care made participants in this study feel frustrated and left them prey to self-doubt. They exhibited a poor sense of responsibility for safeguarding home based care patients from inappropriate symptom and pain management. In line with the current study findings, Merriman and Harding found that a lack of palliative care knowledge had negative effects on the nurses' ability to deal with pain resulting in under treatment of pain (Merriman & Harding, 2010).

5.2.4 Perceived lack of resources

Human and material resource shortages have an impact on the delivery of home based care (Kang'ethe, 2009). Botswana has an ongoing shortage of trained health professionals (Nkomazana et al., 2015). At the inception of home based care there were coordinators for each district and nurses were exclusively allocated to the programme (Lindsey et al., 2003). Nurses provided direct patient care and support to families. Before the relocation process and redesign of the home-based care, Family Welfare Educators (FWE), who were trained community health workers, conducted home visits in the absence of nurses. FWEs substituted when nurses were not available, to conduct patients' assessments and provide support. This FWE support was discontinued after the reorganisation. In the current situation, nurses are being substituted by non-trained, often aged female volunteers who are semi-literate.

There is a substantial body of literature supporting the use of task shifting in HIV/AIDS care. WHO suggested task shifting as a strategy to address human resource shortages in health care settings, especially in resource constrained

countries (World Health Organization, 2008). The study established that in the movement towards task shifting by the health sector to deal with the dramatically increased burden on home care nurses, lay volunteers who were semi-literate with limited or no training were recruited. Nurses have had to incorporate the monitoring and supervision of volunteers into their practice. This significantly increased the emotional burden on home care nurses. Of concern with this finding was that volunteers were often involved in care aspects that projected far beyond their mandate, and were operating without much support.

Due to the complex nature of task shifting, without training, mentoring and proper supervision and support structure it is hard to achieve a good trajectory of patient care outcomes with less trained volunteers (Fairall et al., 2012). If implemented without a clear support, the volunteer task shifting strategy is bound to fail (Kredo et al., 2014). It was evident from the study findings that the relinquishing of home based care nursing responsibilities to non-trained lay volunteers, especially when the task involved handling complex care issues including confidentiality when dealing with PLWHAs, became a source of conflict for home based care nurses. Similar concerns were raised by Ledikwe et al, who documented task shifting and the situation of lay counsellors in Botswana (Ledikwe et al., 2013). These authors raised questions related to quality of service, legal issues and accountability.

An adequate health workforce is an important attribute in bringing about positive health care delivery outcomes (Alam et al., 2012; Nkomazana et al., 2015). As observed by Akintola, the need to scale up the delivery of ARVs increased nurses' reliance on volunteers (Akintola, 2010). Although their job descriptions stated the role of volunteers in home based care should be non-clinical, volunteers

are taking on professional roles such as supervision and monitoring of ARVs, and TB treatments for home based care patients. In this context, the confusion over the roles of and functions of volunteers was perceived to be one of the constraints in the nurses' role, and further contributed to the stress on the nurses.

Burbeck et al. pointed out that although the description of volunteer roles differs in developing and developed countries, the role is intended to be a complementary one, not a substitute for nurses (Burbeck et al., 2014). Volunteers had basic training, and were meant to be assisting families with coping skills and some practical assistance such as cleaning the house, helping with gardening and other home based activities (Ama & Seloilwe, 2011).

Due to the lack of resources to run community home based care programmes, there are a lot of challenges that confront CHBC services in Africa (Kang'ethe & Mangwiro, 2015). Comprehensive home based care needs both human and material resources. Lack of transport hampered health workers, patients and families from travelling to and from health facilities. Shaibu reported that patients living in remote areas could not be easily reached due to lack of transport (Shaibu, 2006). Similarly, participating nurses' narratives suggested that due to inadequate transport, patients' who are poor and from remote areas were not able to go back to the hospital for appointments or to get more opioids to manage their pain.

5.2.5 Perceived Lack of Continuity of Care

Within home based care practice, participating nurses suggested that there was a need for advocacy to support patients and their families during this difficult time. However, the apparent conflict from a perceived mismatch between the loyalty and accountability to the employer and the needs of patient advocacy in home based

nursing care had an impact on the nurses' role to continuously provide quality care. A continuum of care involves a network of resources and services that provide holistic care including referral, follow up and monitoring (Kang'ethe & Mangwiro, 2015).

The Ministry of Health developed referral and discharge forms as a means to promote continuity of care (Lindsey et al., 2003). It was apparent from the participants' narratives that, despite the existence of procedures, there were no referral forms or discharge summaries reaching the clinics especially in the most remote areas. The lack of a clear follow up and discharge summaries from the discharging hospitals reaching the clinics was of great concern.

Nurses in this study were concerned that a lack of information from the healthcare system was damaging their ability to advocate for appropriate on-going treatment for patients. While accepting the necessity of increased home based care for palliative patients, the nurses were concerned that there was no continuity of care strategy for patients released from hospital to be cared for at home. The lack of appropriate linkages between hospitals and the clinics had an impact on continuity of care post discharge. Patients were not easily identified to access-appropriate care services after discharge. Ama (2011), in a study on the experiences and perception of people living with HIV/AIDS under the community home based care programme in Botswana, found that the mean referral time from hospital to community clinic was 39 days within 2 months. Ama's study concluded that issues related to continuity of care and referral process required urgent attention (Ama, 2011).

Good continuity care planning contributes to quality care and safety of patients' care (Olsen et al., 2014). Poor communication between the transferring and

the receiving facility and limited access to essential services to ensure continuity of care were contributing factors to gaps appearing during transition to home based care. Also, the level of engagement of clinics and nurses delivering home based care in discharge and referral system and preparation for the palliative care patients coming to the community was poor. Lack of information about patients' ongoing treatment or care during home care denied nurses the opportunity to advocate, and inhibited them from challenging the doctors' views on treatment options, particularly the level of pain medications offered.

5.2.6 Conclusion

The literature on advocacy and this study's results described the nurse's position in the medical structure as ideal for conducting patient advocacy, as nurses have intimate knowledge of the patient situation and the ability to affect patient outcomes by negotiating between patients and doctors. While this may be the case in ideal nursing situations, nurses' position in the context of Botswana healthcare is less powerful. The CHBC care structure has placed nurses in the forefront of care delivery, but it has not given them influence over pain management decisions, or sufficient numbers to adequately conduct home visits to assess patient needs. As well, patients and communities are not always in agreement with the western concepts of nurses involving themselves in what have previously been exclusively family matters.

Dealing with patients in a home-based care situation includes stressful health and psychosocial issues for the nurses (Pindani et al., 2013). Home based palliative care was a protracted caring experience that caused nurses discomfort and challenged their advocacy competence. These nurses felt an obligation to act as

patients' advocates and were aware of the poor-quality care delivered to patients in their homes. They wished to do what they could in the best interest of the patients. However, their lack of knowledge, doctors' dominance and the conflicts of interest which occurred were factors that weighed on them. While the nurses were confronted with complex ethical issues, a safe space to process the situation was not available. This led to disengagement and a reduction in the quality of care.

5.3 Theme 3: Nurses Dealing with Stigma and Discrimination

Since the beginning of HIV/AIDS epidemic, stigma and discrimination have been identified as major obstacles in HIV/AIDS management. Even though Botswana has enacted laws and regulations which aim to protect PLWHAs, in the current study, participants suggested that policy and related institutional support was lacking. In the 1980s, when the HIV-AIDS epidemic began, the public's response to HIV/AIDS was stigmatisation, discrimination and collective denial (Parker & Aggleton, 2003). Stigma occurs because of a society's rules or sanctions against perceived deviance, such as homosexuality or illicit drug use (dos Santos et al., 2014; Keikelame et al., 2010; Pickles et al., 2009). The consequences of stigma and discrimination are wide ranging. Some people are shunned by family and the wider community, while others perceive or create stigma internally and cut themselves off from society (Setlhare et al., 2014).

The modern understanding of stigma owes much to Erving Goffman, who suggested that when people possess an undesirable or discrediting attribute, this can reduce their status in society, leading to social devaluation and discrimination (Goffman, 1963). Stigma is a powerful means of social control applied by

marginalising, excluding and exercising power over individuals who display certain traits (Mahajan et al., 2008; Parker & Aggleton, 2003; Sagili et al., 2016). Herek built upon Goffman's concept and defined stigma as a lasting, negatively valued circumstance, status or characteristic that discredits and disadvantages individuals (Herek, 2002, p. 596). In addition, Mahajan et al. maintained that the significance stigma has on social interactions is profound (Mahajan et al., 2008). Parker and Aggleton expanded the focus of stigmatising behaviour to a broader level, stating that it is not a consequence of individual behaviour but a social and cultural phenomenon linked to the actions of groups of people (Parker & Aggleton, 2003). In this study, stigma and discrimination was experienced in a similar way to that proposed by Goffman (1963), where the PLWHAs were discredited because of their illness and hence they were shunned by society. The participants in the study related that they sometimes struggled to perform their duty to the patients because of the attitudes of others.

According to Link and Phelan and Hartzendbuehler et al., stigma involves five intertwined components: labelling, stereotyping, social exclusion, and discrimination and power relations (Hartzendbuehler et al., 2013; Link & Phelan, 2014; Link & Phelan, 2006). Negative labelling, which the current study's participants felt was applied to PLWHAs in Botswana, was ingrained in society at large. This labelling creates marginalisation (Fay et al., 2011), disempowerment, status loss and isolation (Link & Phelan, 2014; Link & Phelan, 2001). The social exclusion and marginalisation of PLWHAs occurs when stereotypes about HIV/AIDS are accepted and internalised by the community (Keikelame et al., 2010; Ndinda et al., 2007; Ramirez-Valles et al., 2013). Link and Phelan (2014) maintained that people who are

disadvantaged often give in and accept the societal judgments of their lowered value and the lower place in the society in which their abnormality has placed them. In this study, the outcome was that PLWHAs received less care from their family members and community members, making them more dependent on the nurses, who struggled with the additional load.

In most African countries, HIV/AIDS has been viewed through a moral lens, with PLWHAs being considered sexually irresponsible and personally responsible for their illness (Ulasi et al., 2009). Liamputtong stated that HIV/AIDS 'has been both medicalised as a disease and moralised as stigma' (Liamputtong, 2013, p. 2). In Botswana, an HIV/AIDS diagnosis is accompanied by a strong sense of shame (Bene & Darkoh, 2014; Bene & Darkoh, 2012; Fombad, 2001; Nthomang et al., 2009). Setlhare et al. concluded that, in Botswana, both internal and external stigma occurs at all levels of society (Setlhare et al., 2014). Reports of social distancing and rejection of PLWHAs are numerous in Botswana (Kebaabetswe, 2007; Nthomang et al., 2009; Thupayagale-Tshweneagae et al., 2009). Similarly, the devastating social consequences of stigmatisation for PLWHAs has been identified in this study. Most commonly the form of stigma observed by participants was 'felt' or 'internalised' stigma. This type of stigma resulted in the patient feeling isolated and stigmatised before the actual occurrence of discrimination. Under the influence of self-stigma, patients and families did not feel free to allow home based care volunteers to visit patients or did not want to alert the clinic that there was a sick person in their home. That is, the labelled or demeaned segments of the society were applying the stereotyping to themselves, and assisting in creating their own isolation (Link & Phelan, 2014, p. 3).

Power relations between men and women and cultural norms such as attitudes towards fertility, confidentiality and privacy promote the internalisation of stigma (Geary et al., 2014). The study results show that most of the participants were female, and this has already been demonstrated to increase the prevalence of stigma. Sabone (2015) further observed that Botswana culture frowns on a woman who is proactive in matters of sex especially if those actions inhibit men's pleasure, such as insisting on the wearing of condoms.

Women also appear to have more to lose than men in disclosing HIV status. Thus, "traditional gender norms are characterised by power imbalances between husbands and wives, [with] multiple sexual partnerships are considered the norm for men, but not for women" (Geary et al., 2014, p. 1419). Wives are also often much younger than their husbands and economically dependent, reinforcing the power imbalance. Physical and sexual abuse also occurs, in which spouses are sometimes raped by their HIV positive husbands (Ama, 2011). In this event, if the woman gets infected and discloses her HIV status, she then risks abandonment, economic adversity and an increased risk of further internalised stigma (Sabone, 2015).

5.3.1 Community shame and secrecy

HIV/AIDS stigma may deter individuals from seeking assistance and thus poses a barrier to accessing care (Greeff et al., 2008). Several authors have suggested that negative attitudes towards PLWHAs have posed a challenge to the management of HIV because they have promoted the failure to disclose (Coetzee et al., 2011; Paudel & Baral, 2015; Rodkjaer et al., 2011; Sabone, 2015), and caused reluctance to seek treatment, care and support (dos Santos et al., 2014; Greeff et al., 2008; Jacobi et al., 2013; Ramirez-Valles et al., 2013; Sabone, 2015). Participants in the current

study reported that, in an attempt to maintain family honour, some relatives went to the extent of keeping the presence of PLWHAs in their home a secret, while others were reluctant to take medications openly because of fear of discovery. In other studies in Botswana, researchers observed that most PLWHAs kept their HIV status a secret from health workers and the community for fear of being stigmatised (Bene & Darkoh, 2012; Nthomang et al., 2009; Setlhare et al., 2014; Weiser et al., 2003). An example of exclusion and concealment was described in the case of a very sick child who was denied access to home-based care services when their carers realised that the parents died of an AIDS-related illness. Given these fraught situations, whether to disclose, when to disclose and to whom was a challenge for HIV/AIDS sufferers that impacted on the role of the nurses in this study.

5.3.2 Issues of confidentiality

Participants reported that there were a number of PLWHAs who feared stigmatisation by the community and volunteers, and who did not trust health workers' ability to keep their illness confidential. Concerns have been raised that shifting tasks to less qualified workers could risk both the quality of care and patient confidentiality (Samb et al., 2008). As the participants revealed their experiences in home-based care, it became obvious that sufferers' fear of stigma and being identified sometimes outweighed the fear of being HIV positive. The power of gossip in Botswana village society is deadly. Sabone reported that:

In Botswana, the dilemma centres on the HIV status itself, the diagnosis of AIDS and associated stigma, the burden of treatment and the unpredictable turn of events with the knowledge that AIDS is incurable... failure to breastfeed has come to be associated with

sero-positivity, such that immediately people realise that the new mother is not breast feeding, gossip begins to circulate that the woman has AIDS, together with her male sexual partner(s) (Sabone, 2015, p.120).

Also, there is conflict in the Botswanan handling of AIDS disclosure, because persons usually share health information socially with their family and significant others (Sabone, 2015). Because stigma is attached to AIDS it is not disclosed, forcing relatives and friends to elaborately ignore obvious changes in the PLWHAs health, such as reduced weight, and skin changes, in order to avoid having to recognise the person's illness. Associates were not supposed to know about an AIDS diagnosis unless they were told by the infected persons; but the infected persons in this study were viewed with contempt because they were failing to share their health status.

The study established that nurses were also confronted by confidentiality issues between patients and family members and the community. While people have the right to consent there are occasions when a person's refusal to consent to treatment will raise concern (Cliff & McGraw, 2016). The participants' narratives suggested that the social context of entrenched stigma (which causes families to urge the patient to conceal their HIV status) meant that nurses struggled with feelings of powerlessness and frustration when advocating for home-based palliative care patients. Nurses were often confronted with ethically difficult situations, such as patients refusing to access home-based care services, hiding their HIV-positive status and children being abused because of their status. In these instances, nurses felt the

need to honour the patients' right to self-actualisation while assisting families to accept the patients' illness.

There is another compelling reason to protect the privacy of PLWHAs in Botswana. HIV-positive individuals not only have to manage the disease medically; they must also manage the associated loss of social status and live in the shadow of stigma. In certain societies, a person rejected from the community becomes invisible (Nthomang et al., 2009). Family members of stigmatised people often experience stigmatisation by association (Goffman, 1963). Goffman (1963) posited that such family members may distance themselves from the stigmatised PLWHA family member in response to this stigma. This was the case in this study where family members often abandoned their loved one because of the illness and the fear of retribution from the community.

One of the many challenges highlighted by the participating nurses was the respect of confidentiality while providing care working with untrained volunteers. Confidentiality was viewed as challenging especially when caring for PLWHAs. While nurses often act as patient advocates, potential conflicts of interest may act as barriers to them truly speaking up on behalf of patients (Gazarian et al., 2016). Dealing with untrained volunteers and assigning them responsibilities such as monitoring ARVs conflicted with the nurses' values and often violated their code of practice. The Botswana Public Health Act requires that all positive results must be confidentially recorded by HCWs in terms of notifiable disease obligations (Botswana, 2013, section 114). Such information may only be disclosed with consent (section 115) or in terms of non-consensual disclosure of a person's HIV status. While volunteers were part of the home-based care team, they were not privy

to diagnostic information, adversely affecting their understanding of patient care needs. These problems made it difficult for the nurses to have effective discussions about patient care. Even though there was shared confidentiality, the right of the patients must be respected, which often leads to ethical dilemmas. The nurses felt that when confidentiality was adhered to they were frustrated by lack of inclusion of volunteers in providing adequate and accurate information about the patients, and this also jeopardised continuity of care. However, the Act further clarifies shared confidentiality (section 115) that disclosure to other HCWs who are directly involved in the care of the PLWHA have the right to know the status (Botswana, 2013). The study findings concluded that nurses felt the burden in dealing with such conflicting principles within their care and could not speak openly about it.

5.3.3 Response to HIV Stigma by infected nurses

From early in the AIDS epidemic, a series of powerful stories were connected with AIDS, including that HIV was a result of immoral behaviour, such as promiscuity and homosexuality (Ebied, 2014). Thus, people of more elevated social status characterised AIDS sufferers as ‘other people- not me’. The burden of these attitudes was profoundly felt by the nurses, due to their elevated social status and professional responsibilities. In their study, Jackson et al. observed that ‘othering’ can further promote the separation of certain persons from normal culture and break up the existence of the already oppressed and marginalised group (Jackson & Daly, 2011, p.108). Much of the available literature examines the process and functions of stigmatisation from the perspective of the general population. Not much has been written on stigma and discrimination and its impact on nurses who become infected, and how this concept of othering impacts upon them.

According to Goffman (1963), although a stigmatised person may see themselves as normal, they will probably recognise that others treat them differently. Goffman further suggested that being regarded as normal is core human behaviour. Therefore, infected nurses in Botswana were motivated to hide their HIV status to preserve their social status, and thus remain in the category of society recognised as 'normal'. The current study suggests that health care workers in Botswana often hold negative views of PLWHAs, mirroring those of the community at large. Stigma and discrimination in health settings takes many forms, including the denial of health care, unjust barriers to service provision, abuse and other forms of mistreatment (Ebied, 2014; Farber et al., 2014; Nyblade et al., 2009; Smit et al., 2012). The violation of autonomy and other forms of stigma and discrimination encountered by PLWHAs had a bearing on how nurses dealt with their own HIV positive status. Furthermore, the study established that stigma was perceived as a persistent force that discouraged nurse testing and created barriers to nurses' HIV/AIDS-related care and support, including CHB care and access to ARV therapy. The perception was that despite the available programs aimed at HIV/AIDS mitigation, secrecy still dominated the actions of infected nurses.

Studies on stigma and discrimination among nurses have demonstrated that HIV/AIDS stigma among nurses was prevalent in African countries due to the high rates of HIV in the general population (Asuquo et al., 2013; Chirwa et al., 2009; Dieleman et al., 2007; Kyakuwa & Hardon, 2012). While negative responses to HIV/AIDS are by no means inevitable in Botswana, nurses are bound to feel uncomfortable with it. Designation of some phrases or connotations to PLWHAs was reported to be common amongst nurses in this study, resulting in the nurses'

discomfort at being classified in accordance with those attributes. Nurses were not immune to internalising negative social perceptions, and sometimes anticipated being stigmatised or discriminated against.

The fact that people may feel or internalise stigma even when there are no obvious discriminatory actions taking place makes dealing with stigma complex (Herek, 2002; Weiss, 1993). Longitudinal studies on the effects of stigma on mental illness have indicated that increased levels of internalised stigma are associated with “lower levels of hope, empowerment, self-esteem, self-efficacy, quality of life and social support...[and] internalized stigma is positively associated with psychiatric symptom severity and is negatively associated with treatment adherence” (Livingston & Boyd, 2010, p. 2157). A study specifically dealing with internalised stigma in AIDS sufferers in South Africa mirrored these findings, indicating that internalised stigma was significantly correlated with cognitive-affective depression, particularly in males (Simbayi et al., 2007).

The research suggests that HIV-infected nurses fear stigma, and this drives behaviour. Almost all the participants in this study indicated that nurses were fearful because they were not sure of the reactions of people around them. For example, nurses opted not to use free government services to purchase ARV, and were willing to spend days away from work, travelling to distant clinics for check-ups or to access medication, in order to avoid others becoming aware of their situation. Similarly, Kyakuwa and Hardon reported that none of the nurses interviewed in their study received treatment at the clinic in which they worked, citing not only practical reasons but also fear of social stigma due to the association of HIV with promiscuity and unsafe sex (Kyakuwa & Hardon, 2012). The impact of not testing early or

seeking treatment caused further strain on the system, which already suffered from a shortage of qualified nurses, as nurses left the workforce unable to work.

However, according to the participants' narratives, nurses seem to suffer more self-stigmatisation than the general population. Nurses still suffer in secrecy, and are prey to feelings of social isolation and alienation.

In this study, negative stigmatising attitudes were amplified by the power the nurses had over the community, and the status they held. Some participants made comment such as 'nurses need to know better'. It was apparent that these feelings created barriers to disclosing their HIV/AIDS status to their colleagues or employers when they needed support.

Singling out HIV as a target for confidentiality may contribute to stigma rather than mitigate it. Uebel et al. suggested that incorporating HIV services into comprehensive health care services instead of creating specialised ARV therapy clinics would assist in reducing stigma by 'normalising' the disease (Uebel et al., 2007). Bemelmans et al. observed that having staff clinics combined with HIV support programmes enhanced ARV therapy adherence and promoted successful utilisation of services by health workers (Bemelmans et al., 2015).

5.3.4 Conclusion

Although there was substantial evidence of health care workers' stigmatisation of HIV-positive patients in the early years of the disease, there is less documentation available in Botswana on how health care workers' attitudes towards HIV care have changed with increased access to ARV therapy and exposure to HIV education and training. This lack of documentation is significant, as its absence makes it difficult to gauge changes in the psyche of the providers, and to understand

the social dimensions of the provision of care in different settings (Rajaraman & Palmer, 2008). A study in Côte d'Ivoire showed that, despite the availability of ARV therapy, HIV/AIDS continues to be perceived as an impending death sentence, and PLWHAs face widespread stigma resulting in name calling, rejection, isolation and social discrimination (Rajaraman & Palmer, 2008).

In line with other research that found that stigma and discrimination are associated with negative health outcomes for PLWHAs, including poor ARV therapy adherence, the current study's findings suggest that Botswana should continue to strengthen HIV/AIDS programmes to combat stigma. Unravelling the aspects of stigma that impede uptake and adherence to ARV therapy, and the complex interactions among them, will enhance the efficacy of stigma reduction interventions (Mukolo et al., 2014). The availability of ARV therapy and subsequent changes in perception of HIV/AIDS from a perceived death sentence to a manageable chronic disease has led to a decrease in stigma and discrimination in high-income countries (Peltzer & Ramlagan, 2011).

In response to this pervasive stigma, the Second Botswana National Strategic Framework for HIV/AIDS 2010-2016 recognised the need to address all forms of stigma and discrimination:

Stigma and discrimination severely constrain the ability to maximise the impact of many interventions by reinforcing existing negative social constructs, norms and practices that further disadvantage and marginalize groups of people, reducing their overall integration into the national response. They limit the delivery of, and access to relevant services thereby increasing

the risk and vulnerability to HIV infection... (Botswana. National AIDS Coordinating Agency, 2009, p.12)

In Strategic Priority 3 (Systems strengthening) lists an implementation strategy (number 13) to “build capacity to address HIV and AIDS stigma and discrimination” (p.24).

Tackling internalised stigma includes addressing the emotional wellbeing of affected individuals. Self-imposed stigma can be addressed by strengthening self-support groups for people living with HIV, fostering support groups, building family support, and addressing stigma in the workplace (Brouard & Wills, 2006). The drivers of stigma can be addressed with any PLWHA, to create awareness of what stigma is and the benefits of reducing it: fostering motivation for change, addressing fears and topics that are linked to fuelling stigma and discrimination based on gender and sexuality, and providing the skills to challenge stigma and promote self-acceptance in individuals.

Chapter 6: Conclusions, Recommendations and Limitations

6.1 Introduction

This study has provided an interpretation of nurses' experiences while delivering palliative CHBC to PLWHAs and related chronic illnesses in Botswana. PLWHAs present a unique challenge to nursing practice. The study acknowledges the difficulties faced by these nurses and considers how their challenges may be addressed. With the move towards community home based care for PLWHAs, nurses are now expected to deliver palliative care in an often poorly resourced environment with limited training and support. While the current study showed that nurses are willing to provide holistic care, they lack knowledge about palliative care principles and procedures to assist them attain this goal. Palliative care is an emerging discipline in the Botswana health care system, and would benefit from research to inform nursing policy, education and on-going research.

The major implication of this research is that nurses who interact with PLWHAs need increased awareness and understanding of the effects of caring for these patients. They also need to be aware of the on-going emotional and psychological issues involved for the patients and for themselves. Better ongoing education is essential to developing this understanding and its practical expression.

The findings also indicate the significant effects of stigma on nurses. The discovery of perceived or self-stigma among infected nurses, and their stated reluctance to disclose and utilise home-based care services revealed a significant issue to be addressed. HIV-positive nurses did not easily access government services, and most end up unwell. Targeted interventions are necessary to deal with

stigma and discrimination among health care workers. If nurses are serious about leading by example and normalising the disease, then they should openly demonstrate health-seeking behaviours by being tested and utilising government services.

Because nurses in this study perceived that lack of engagement in management decisions affected their practice, it is critical that nurses' level of involvement in administrative health care innovation is increased. This will allow them to express their views and manage change better. Nurses should be supported to advocate for responsive workplace policies, speak up against stigma and actively pursue better education in communication skills and interpersonal relationships. The Nurses Association of Botswana should continue to participate in the debate, and continue to provide professional support for nurses.

The findings from this study provide evidence to suggest that the context in which home based care is delivered, untrained volunteers are taking full responsibility. These findings demonstrate the importance of ensuring that volunteers are adequately prepared to carry out patient care in the community.

6.2 Recommendations for Nursing Policy

- A major recommendation emerging from the study is for the health care system to manage change more effectively. This could be achieved by improved consultation with experienced practicing nurses to include the development of palliative care guidelines, the development and implementation of a risk assessment framework to inform any change process, and the articulation of a clear, well-informed vision of the Ministry's

larger goals and new practice initiatives (including mapping, detailing, educating and communicating the changes).

- The minimisation of any negative effects of the change process on nursing staff should also be a priority. An on-going evaluation process should be embedded in policy to inform all future health care system decisions. Underpinning this approach should be a departmental commitment to providing the required education and support to facilitate the implementation of change. The establishment of a mentoring programme for all new staff should be developed to further support change, a program which includes new managers, who can be abruptly thrown into ‘acting’ roles or abruptly promoted beyond their level of experience.
- Increased access to resources is also recommended, specifically access to clinic vehicles, ambulances and pain medication (e.g., opioids) in remote and rural areas. In the absence of strong pain medication and alternative therapies. The study would recommend the use of alternative or traditional methods which may not replace opioids but can have therapeutic effect on the patient’s mind.
- Another resource that requires development is the CHBC volunteers program. The scope of recruitment needs to be extended to encourage more men into the program, and to attract younger people, especially those living in rural and remote areas. The volunteer program needs to supply comprehensive training, structured visiting rosters and regular opportunities for de-briefing and interaction with nursing staff.

- Strong community partnerships need to be reactivated to ensure genuine collaboration with the local community. The imposition of a centralised, bureaucratic system seems to have depressed the make-do-and-mend attitude that previously informed community operations. This is particularly important when considering the transportation and treatment of patients from remote areas.

6.3 Recommendations for Education

- Participants described a disconnect between palliative care training and practice, and reported missing key concepts during training due to the timing and length of the courses. Therefore, both appropriate nursing undergraduate programmes and on-going professional training packages are required to increase nurses' palliative care knowledge. Nursing education specifically needs to enhance nurses' knowledge of pain assessment and symptom management. This is particularly important for the on-going management of PLWHAs who receive palliative care in the community. Also, future formal and informal education and training in palliative care should encompass the nurses' role in advocacy and HIV/AIDS, as a compulsory area of study.
- Improving the palliative care knowledge of nurse managers would be an important milestone in improving CHB care. Topics needing enhancement include overall end of life treatment, pain assessment and management techniques, nurse/doctor and nurse/patient communication strategies, and ethics. Attention to these aspects would further enhance nurses' level of awareness and maintain their confidence while delivering CHB care.

- The MoH and training institutions should address the performance gap that occurs between theory and practice in CHBC by supporting nurses to practice what they have learned in their undergraduate programmes and from professional development courses. Compulsory professional development workshops on palliative care should also be made available to volunteers.
- A country-wide learning community for practitioners of community palliative care nursing should be established. It is essential for nursing education institutions to support professional development for nurses, and to create an environment that encourages nurses to pursue further studies on palliative care. Particular care must be paid to ensuring this community extends to nurses in remote and rural areas, in order to ensure that they have access to both practical and emotional support. Such attention will increase their motivation and confidence.

6.4 Recommendations for Further Research

Because phenomenological research is conducted to reveal the experiences as perceived and interpreted by participants, the aim of undertaking such research is to develop new knowledge, rather than to test hypotheses. This was the basis of this current study, and considering the strengths and limitations of the study, a number of recommendations have been suggested for further research.

- The expansion of this Botswana study to larger and different health care settings involving nurses, doctors, volunteers, lay counsellors and Health Education Assistants is recommended.

- In order to assess the role of nurses in palliative care in a broader sense, there is a need to conduct a comparative study among acute care settings, CHB and hospice centres.
- Patient advocacy in the context of home-based care requires further examination. This is a specific area of interest, as nurses play an advocacy role for patients and their families. The attitudes of nurses, nurse managers and nurse educators towards patient advocacy need to be documented with a view to promoting agreement about the nurse role in patient advocacy.
- Research is necessary to examine the experiences of HIV positive nurses with regard to stigma and discrimination. In order to prevent the further reduction of the nursing workforce, it is imperative to conduct studies on nurses who are HIV-infected, to highlight significant issues and avenues for support.

6.5 Limitations of the Study

Factors such as relocation of services from the Ministry of Local Government to the Ministry of Health had an effect on the research. The movement of nurses from one clinic to another meant that some nurses who were new in the clinic were the ones nominated by management to participate in the study.

Despite reassurances that information shared would be kept in confidence, some participants felt unable to contribute fully while being tape recorded. Some participants seemed to be more confident talking when the recorder was switched off. This meant that the researcher had to remember these parts of the conversation and note them down by hand afterwards. Unfortunately, this could mean that some

important data was missed. However, the researcher maintains that the methodology suited the purpose of the investigation

Although this was a small sample from a discrete area of Botswana, the richness of data collected provided compensation. Therefore, while the views expressed in the thesis might not be representative of all CHBC programmes and organisations in Botswana, the accounts reported in the current study offer the opportunity to understand the views of those interviewed. Factors such as relocation of services should be further investigated. The support for nurses participating in home based care during change process should be considered and the precise influences of these factors need further investigation.

6.6 Implications for Nursing Practice

This study aimed to explore the phenomenon of providing home-based care to PLWHAs in Botswana from the perspective of nurses delivering palliative care to such patients. Currently, research in the general field of palliative care relating to nurses' experiences in Botswana is lacking. Through this study, several important issues that are critical to improving the professional practice of nurses who provide palliative CHBC to PLWHAs have been revealed.

The major implication of this research is that nurses who interact with PLWHAs need increased awareness and understanding of the effects of caring for these patients. They also need to be aware of the on-going emotional and psychological issues involved for the patients and for themselves. Better ongoing education is essential to developing this understanding and its practical expression.

The findings also indicate the significant effects of stigma on nurses. The discovery of perceived or self-stigma among infected nurses, and their stated

reluctance to disclose and utilise home-based care services revealed a significant issue to be addressed. HIV-positive nurses did not easily access government services, and most end up unwell. Targeted interventions are necessary to deal with stigma and discrimination among health care workers. If nurses are serious about leading by example and normalising the disease, then they should openly demonstrate health-seeking behaviours by being tested and utilising government services.

Because nurses in this study perceived that lack of engagement in management decisions affected their practice, it is critical that nurses' level of involvement in administrative health care innovation is increased. This will allow them to express their views and manage change better. Nurses should be supported to advocate for responsive workplace policies, speak up against stigma and actively pursue better education in communication skills and interpersonal relationships. The Nurses Association of Botswana should continue to participate in the debate, and continue to provide professional support for nurses.

Ineffective supervision due to the deployment of inexperienced nurse managers was also revealed in this study. Participants perceived that managers did not have adequate information about home-based care. The implication for nursing practice is that, in order to re-establish nurses' respect for supervisors and ensure patients had the best quality of care in their home environments, provision of proper training and mentorship of managers is required.

This study has highlighted the needs of nurses and volunteers delivering palliative care in Botswana. Feedback from this study will be taken to the MoH in Botswana, where it has the potential to affect the design of future home-based care

services in Botswana. There is a need for a collaborative approach between palliative care providers, including nurses, doctors and other health professionals. Equity issues associated with distance and location, have had a negative impact on the delivery of services, and complicate communication. To improve nursing practice in geographically isolated areas, the CHBC programme need be better funded, and nurses better supported, with attractive incentives (including salary) to promote retention of nurses.

The current study has established that access to pain medications in remote and rural areas is either limited or non-existent. This is due to the lack of drugs and restrictive legislation, and inadequate facilities for safe storage of Schedule 8 drugs. This has major implications for the care of patients at the end-of-life. The inequity engendered by this lack of service must be addressed.

6.7 Conclusion

The organisational change and restructuring that occurred prior to the study had a significant effect on the way nurses deliver CHBC to PLWAs. The role of CHBC nurses within the organisation was found to be minimal in terms of decision-making and advocacy. Home-based care nurses reported a sense of powerlessness in providing adequate palliative care to PLWHAs and other patients cared for in the community. The nurses expressed frustration due to a lack of adequate support for the delivery of home-based care. The study has identified that although nurses value the work done by volunteers, their lack of training and support was frustrating. These issues, as well as nurses' lack of theoretical knowledge of palliative care and a poor understanding of their advocacy role, inhibited their role as patient advocates.

Even though the nurses grieved over the poor quality of care they could deliver and the lack of resources they could provide to their patients, Botswana's home care nurses have continued to hold the line in the fight against HIV/AIDS. Nursing professionals are generally not resistant to change, provided they have enough resources and adequate support (Tingvoll et al., 2016).

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Appendix A: Confirmation of Candidature

14.06.2010

JAMES COOK UNIVERSITY Graduate Research School

RECEIVED
20 APR 2011
Graduate Research School

Confirmation of Candidature Report Form

Upgrade of candidature No Yes If yes, please note the following requirement:

Domestic student: A PhD assessment form must be completed by the Head of School and attached for approval by the Higher Degrees by Research Sub-Committee.

International student: A PhD application form must be lodged with the International Student Centre prior to commencing the Confirmation of Candidature process.

Full Name: T. SHERISO, DAISY MOSARE CO	Date project proposal submitted to Graduate Research School: NURSING, MIDWIFERY & Nutrition
Student Number: 12415157	Date of Confirmation Seminar: 12/04/11
Degree (e.g. MSc): Ph.D	

This form should be completed by you, the candidate, in consultation with your Supervisory Committee at the time of your confirmation of candidature.

1. You should complete Section 1 and 2 (The Project Proposal and Candidate's Comments)
2. Your Principal Supervisor should then complete Section 3 (Supervisor's Comments)
3. Section 4 should then be completed jointly with your Principal Supervisor (Confirmation Report Checklist and Checklist of Research Compliances). The process of completing this Section jointly is very important.
4. Sections 5 and 6 are to be completed by your Supervisory Committee following the confirmation seminar and after a meeting with you to discuss your progress.
5. The Summative Evaluation checklist is to be completed by your Supervisory Committee in order to provide further information on your progress and it also provides a further means of assessment for Heads of School when ranking their students for scholarships. The outcome of this evaluation is to be discussed with you at the meeting.

Failure to complete your Confirmation of Candidature by the due date may result in termination of your candidature as well as any scholarship you may hold.

Requests for extensions to the provisional candidature period must be made through your Head of School to the Graduate Research School before the due date.

DO NOT SUBMIT THIS FORM IF PROVISIONAL CANDIDATURE IS TO BE EXTENDED

- In addition to the Confirmation of Candidature report, you may make a confidential written report to the Dean of Graduate Research Studies about any concerns relevant to your candidature.
- Throughout your candidature, you can expect support and guidance to be readily at hand in your School, primarily from your Principal Supervisor.
- If you have problems you are unable to discuss with your Supervisors, then in the first instance you should approach the School Postgraduate Liaison Officer or Director of Research Training, Head of School, or your Research Student Monitor.
- If the problem cannot be resolved contact the Dean of Graduate Research Studies through the Graduate Research School. (Phone 47 815661)

CONFIRMATION OF CANDIDATURE PROCEDURE

- a. Please check your candidature details through eStudent.

Requests for amendments to candidature details should be made on a Variation of Candidature form which can be found at: <http://www.jcu.edu.au/office/grs/links/forms.html>

- b. Refer to the Graduate Research School Handbook Section 4 (Terms of Candidature) for details.

Briefly you will need to:

- ✓ 1. Prepare a written project proposal of at least 2,000 words. (Guidelines below.)
- ✓ 2. Submit a substantive piece (or pieces) of scholarly writing and /or substantive progress towards artistic work related to the research additional to the project proposal, to be evaluated by your Principal Supervisor and Head of School.
- ✓ 3. Make an oral presentation on the project proposal of at least 30 minutes duration plus up to 30 minutes of question time in a school postgraduate seminar or similar forum.
4. Have met any special conditions noted on your offer and necessary for confirmation of candidature.

Section 1. The Project Proposal (Approximately 2,000 words)

Please submit your project proposal to your school initially.

Check with your Principal Supervisor or the School Postgraduate Liaison Officer (or Director of Research Training) for the specific school requirements for confirmation of candidature.

The final copy of your project proposal should be sent to the members of your Supervisory Committee at least five working days before the seminar date.

An electronic copy should be forwarded to the Graduate Research School (email Sue.Mldson@jcu.edu.au) for the University records and for checking by the University's statistician (where appropriate).

The content and structure will vary across disciplines but should include:

1. A concise statement of the research question(s).
2. A critical summary and analysis of relevant literature (you must be able to demonstrate a capacity for critical review).
3. An explanation of the conceptual framework to be used and/or a summary of experimental methods and equipment requirements (as appropriate for your discipline).
4. A summary of progress to date including preliminary data, resources developed etc.
5. An argument for the relevance and importance of the study.
6. A proposed schedule and timeline for the phases of the study, including a date for submission.
7. A risk analysis outlining the risks of your study not being successful and a plan to manage these risks.
8. A brief bibliography.
9. A list of publications produced or presentations made during your candidature to date.
10. Provide evidence of papers "In Review".

Section 2. Candidate's Comments

1. How often do you consult with your supervisor(s) WHEN ON CAMPUS.
 Daily Weekly Monthly Other
- To what extent has this met your needs. MY NEEDS WERE FULLY MET
2. Have there been any interruptions to your supervision. Yes No
 If Yes, please elaborate.....
3. Have there been any difficulties affecting the progress of your work. Yes No
 If Yes, please elaborate.....
4. Would you like additional help in the area of language/writing/communication skills. Yes No
 If Yes, please elaborate I have been in touch with Liz Tjans
5. Do you anticipate any difficulties completing in the allowed time. Yes No
 If yes, what factors (including employment or other commitments) are likely to delay completion.

Section 3. Supervisor's Comments

Please ensure the student checks his/her candidature details through Student One.

1. Is the School able to provide all necessary facilities for the candidate's research during the coming year. Yes No
2. Are supervision arrangements for the candidate finalised for the whole of the coming year. Yes No
3. Has the candidate submitted a substantive piece of writing in addition to the project proposal? Yes No
4. Has the candidate provided evidence of papers "In Review". Yes No
 If you have ticked No to any of the above, please comment: WILL PLAN ARTICLES SOON
5. Has the candidate: (Please circle one number)
- | | | | | | | | |
|--|----------------|---|---|---|---|---|-----------|
| diligently and effectively applied himself/herself to his/her project | Unsatisfactory | 1 | 2 | 3 | 4 | 5 | Excellent |
| shown initiative consistent with the requirements of the research program/course and level of study | Unsatisfactory | 1 | 2 | 3 | 4 | 5 | Excellent |
| made satisfactory progress to date | Unsatisfactory | 1 | 2 | 3 | 4 | 5 | Excellent |
| shown that working at the pace of provisional candidature he/she will be able to complete the thesis by the due date | Unlikely | 1 | 2 | 3 | 4 | 5 | Likely |
6. Have any of the following issues affected progress during the provisional period of candidature:
- | | | | |
|--|---|---|----------------------------------|
| <input type="checkbox"/> Academic background | <input type="checkbox"/> Health/Personal | <input type="checkbox"/> Project infrastructure | <input type="checkbox"/> Funding |
| <input checked="" type="checkbox"/> English(written or oral) | <input type="checkbox"/> Access to current literature | <input type="checkbox"/> Understanding of work expected | |
- Please indicate what steps you have taken to help overcome these problems. IN TOUCH WITH LIZ TYNAN - OTHER RESOURCES

6. Supervisor validation of data collected by student:

What steps is the supervisory team planning to take/ taking to ensure that the data associated with this degree project are authentic. Please indicate:

- Regular supervision sessions
- Occasional use of plagiarism software on thesis drafts
- Spot checks of lab books, field notes, research journals
- Spot checks on coding of qualitative data
- Spot checks on print outs of statistical analysis
- Accompanying student on occasional field trips especially pilot studies
- Regular contact with students during remote fieldwork
- Ensuring data storage arrangements comply with University ethics requirements

7. Risk to student of trauma from the research project:

Is the student at risk of trauma from the process or findings of the research? yes no

If yes, what steps is the supervisory team planning to take/taking to encourage the student to access appropriate counselling support.

.....

4. CHECKLIST OF RESEARCH COMPLIANCES (To be completed by the Candidate)

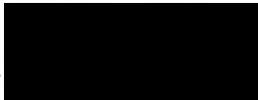
	Yes	No
1. Does your research work include fieldwork? <i>If No, go to question 2.</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
1.1 Does your field work involve any of the following:		
a) fieldwork at an on campus field site? Please specify	<input type="checkbox"/>	<input checked="" type="checkbox"/>
b) fieldwork at an off campus urban location? Please specify <u>IN AFRICA</u>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
c) fieldwork at an off campus marine location? Please specify	<input type="checkbox"/>	<input checked="" type="checkbox"/>
d) fieldwork at an off campus rural freshwater location? Please specify	<input type="checkbox"/>	<input checked="" type="checkbox"/>
e) fieldwork at an off campus remote location? Please specify	<input type="checkbox"/>	<input checked="" type="checkbox"/>
f) fieldwork at an off campus overseas location? Please specify <u>AFRICA</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
1.2 Have you been briefed on fieldwork procedures appropriate to your discipline and/or satisfactorily completed a fieldwork induction course?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
1.3 Have you completed the requisite risk assessment procedures with respect to fieldwork associated with your research project?	<input type="checkbox"/>	<input checked="" type="checkbox"/>

- 1.4 Have you obtained the relevant permits in respect of:
- a) State regulations?
 - b) Federal/Commonwealth regulations?
 - c) Local community requirements? (especially important if you are working with an Indigenous community)
- 1.5 Does your research project involve situations which require protection against infection/s and/or disease through vaccination?
- 1.6 Does your research involve data collection in overseas countries?
- 1.6.1 If your research involves data collection in overseas countries
- a) have you obtained the necessary authority to do so?
 - b) have you obtained the necessary permits to do so?
- 1.7 Have you obtained the appropriate health cover to support your overseas trip?
2. Do you intend to import materials associated with your research?
If No, go to question 3

CHECK LIST FOR RESEARCH COMPLIANCES CONTINUED

Yes No

- 2.1 If you intend to import materials have you obtained all necessary clearances?
- 2.2 Do you intend to export materials associated with your research?
- 2.3. If you intend to export materials have you obtained all necessary clearances?
3. Have you completed a workshop on ethical research practice as required for confirmation of candidature*
4. Does your research project or its location involve issues of human or animal ethics?
If No, go to question 5
- 4.1 Have these been identified and appropriate protocols discussed with your Principal Supervisor?
- 4.2 Have you made application for appropriate ethics approvals? *IN PROCESS.*
- 4.3 Has ethics approval been granted? **
5. Does your research project or its location involve cultural sensitivities?
If No, go to question 6
- 5.1 Have these been identified and appropriate protocols discussed with your Principal Supervisor?
6. Does your research project or its location involve Indigenous people or matters? N/A
- 6.1 Have these been identified and appropriate protocols discussed with your Principal Supervisor?
- Are you and your Principal Supervisor aware of the Indigenous research protocols workshops coordinated by the School of Indigenous Australian Studies to educate Research Higher Degree candidates and their Supervisors as to how they might conduct their research in an ethical and culturally sensitive manner.

Signature of Candidate. 

Date. 12/04/11

*Final approval for confirmation of candidature will not be granted until:
 * a workshop on ethical research practice has been completed.
 ** any required ethics approval that is integral to the project has been obtained.*

Section 5. Confirmation of Candidature

Evaluation of Seminar (to be completed by the Supervisory Committee)

Theoretical Background (Circle one)

- Clear statement of aims of research Appropriate Inadequate N/A
- Understanding of Theory Appropriate Inadequate N/A
- Fluency of Presentation Appropriate Inadequate N/A
- Development of Hypotheses/Research Questions Appropriate Inadequate N/A
- Overall Comprehensiveness Appropriate Inadequate N/A
- Project proposal demonstrates a capacity for critical review Appropriate Inadequate

Methodology

- Appropriateness of Method to Study Appropriate Inadequate N/A
- Understanding of Methods Appropriate Inadequate N/A
- Training in Use of Methods Selected Appropriate Inadequate N/A
- Has a research plan been prepared Appropriate Inadequate N/A
- Have the risks to the project been identified and a plan to manage the risks been included Yes No

Data Analysis (May be marked as "not appropriate")

- Appropriateness of Analysis Appropriate Inadequate N/A
- Clarity of Presentation Appropriate Inadequate N/A
- Relation of Outcome to Hypotheses/Research Questions Appropriate Inadequate N/A

Conclusions

- Summary Appropriate Inadequate N/A

Academic Writing Skills

- Assessment of written piece of work Appropriate Inadequate
- Participation in the writing skills program recommended Yes No

Additional Factors

- Is the project multi-disciplinary? Yes No
- Does the project involve working with human communities? Yes No
- If so, is appropriate supervision in place? Yes No N/A
- Has a timetable for completion been prepared? Yes No
- Has any required ethical (animal, human including Indigenous) clearance been obtained? Yes No N/A
- Have assurances been obtained regarding future availability of material necessary to the project? Yes No N/A
- Are research assistants to be used? Yes No N/A
- If so, is student aware of university policy¹? Yes No N/A
- Has the student undertaken coursework/skills training as recommended during the skills assessment early in the candidature? (e.g. writing, statistics, computing) Yes No
- Is it necessary to do more? Yes No
- If yes, please indicate under additional comments below.
- Is the Supervisory Committee satisfied that sufficient funds are available to support the proposed research? Yes No
- If not, how is this problem addressed?
- Is adequate infrastructure for the project available at JCU Yes No
- If not, how is this problem addressed?

Supervisory Committee Report

1. The project proposal and additional substantive written work has been received and approved. Yes No
2. The candidate has made a presentation of his/her proposed research at a postgraduate seminar or similar school forum. Yes No
3. The candidate has met any special additional requirements noted on enrolment and required for confirmation of candidature. N/A Yes No
4. The Supervisory Committee has met with the candidate after the seminar to review his/her progress and feedback has been given on the project proposal, supervisory arrangements and resources available. Yes No

¹ *ie Paid Research Assistants may be used for routine processing work but must not contribute significant intellectual input to a research degree.

**Summative Evaluation of Confirmation of Candidature –
Doctor of Philosophy (including upgrade from Masters by Research)¹**

<i>Formative recommendation</i>	<i>Evaluation of standard of performance (please tick a box)</i>
<input checked="" type="checkbox"/> Recommendation CCU.² Confirmation of Candidature	<input type="checkbox"/> Group A – Outstanding. Outstanding in all components of the Confirmation of Candidature <input checked="" type="checkbox"/> Group B – Excellent. Excellent and original approach to the research project but falling outside the very best <input type="checkbox"/> Group C – Very Good. Solid performance in all components of the Confirmation of Candidature but demonstrating less flair and originality than Groups A or B <input type="checkbox"/> Group D – Good. Either: (1) Variable performance which on balance is of an appropriate standard and/or (2) Confirmation of Candidature has been delayed >12 months FTE without substantive reason(s) and permissions
<input type="checkbox"/> Recommendation CCA.¹ Confirmation of candidature when: ethics or other necessary approvals have been confirmed and/or additional specified work has been completed and formally approved by the Head of School.	<input type="checkbox"/> Group A – Outstanding. Outstanding in all components of the Confirmation of Candidature; additional requirements purely administrative e.g. ethics approval <input type="checkbox"/> Group B – Excellent. Excellent and original approach to the research project; additional requirements either: (1) purely administrative e.g. ethics approval or (2) indicative of inexperience e.g. rescaling of project because it is too ambitious <input type="checkbox"/> Group C – Very Good. Solid performance with respect to of the Confirmation of Candidature but demonstrating less flair and originality than Groups A or B; additional requirements either: (1) purely administrative e.g. ethics approval or (2) indicative of inexperience e.g. rescaling of project because it is too ambitious <input type="checkbox"/> Group D – Good. Variable performance which on balance is of an appropriate standard; additional skills required e.g. ESL, statistics; and/or Confirmation of Candidature has been delayed >12 months FTE without substantive reason(s) and permissions
<input type="checkbox"/> Recommendation CCR.³ Reconsideration of Confirmation of Candidature within six months of the Initial presentation, subject to work undertaken to the satisfaction of the Higher Degrees by Research Sub-Committee. A second seminar presentation may be specified.	<input type="checkbox"/> Group E Proposed research not of sufficient scope for PhD or unrealistic in terms of resources and timeframe; candidate apparently has required skills; situation potentially redeemable within 6 months <input type="checkbox"/> Group F Proposed research suitable for PhD but candidate deficient in essential skills; situation potentially redeemable within 6 months
<input type="checkbox"/> Recommendation CCM⁴ Candidature for Doctoral studies be replaced by candidature for Research Masters studies with the provision that the applicant may re-apply for upgrade to PhD candidature within six months	<input type="checkbox"/> Group G Proposed research not of sufficient scope for PhD; this assessment must be checked via peer review of proposal by person with appropriate expertise independent of supervisory team; candidate appears to have necessary skills for Research Masters candidature, recommend candidate change enrolment to Research Masters or leave enrolment unchanged at Research Masters with potential for formal reconsideration of PhD candidature within 6 months <input type="checkbox"/> Group H Proposed research suitable for PhD but candidate lacks essential skills for PhD but has skills necessary for Research Masters candidature, this assessment must be checked with viva conducted by person with appropriate expertise independent of supervisory team; recommend candidate change enrolment to Research Masters or remain enrolled in that degree with potential for formal reconsideration of PhD candidature within 6 months

¹ Ratings recorded here will be used for grading applications for JCU stipend and fee-subsidy scholarships if required

² Upgrade from Masters permitted

³ Upgrade from Masters not permitted

<input type="checkbox"/> Recommendation CCF. The candidate be asked to show cause why his or her candidature as a research higher degree student should not be terminated.	<input type="checkbox"/> Group I Candidate appears not to have skills necessary for research higher degree student and is unlikely to gain such skills within 6 months; this assessment must be checked with viva conducted by person with appropriate expertise independent of supervisory team; subject to result of viva, HDRSC will ask candidate to show cause why his or her candidature should not be terminated; HDRSC may recommend candidate change enrolment to coursework masters, graduate diploma, graduate certificate.
--	--

**Summative Evaluation of Confirmation of Candidature –
Masters by Research**

<i>Formative recommendation</i>	<i>Evaluation of standard of performance (please tick a box)</i>
<input type="checkbox"/> Recommendation CCU. Confirmation of Candidature	<input type="checkbox"/> Group A – Outstanding. Outstanding in all components of the Confirmation of Candidature <input type="checkbox"/> Group B – Excellent. Excellent and original approach to the research project but falling outside the very best <input type="checkbox"/> Group C - Very Good. Solid performance in all components of the Confirmation of Candidature but demonstrating less flair and originality than Groups A or B <input type="checkbox"/> Group D – Good. Either: (1) Variable performance which on balance is of an appropriate standard and/or (2) Confirmation of Candidature has been delayed >8 months FTE without substantive reason(s) and permissions
<input type="checkbox"/> Recommendation CCA. Confirmation of candidature when: ethics or other necessary approvals have been confirmed and/or additional specified work has been completed and formally approved by the Head of School.	<input type="checkbox"/> Group A – Outstanding. Outstanding in all components of the Confirmation of Candidature; additional requirements purely administrative e.g. ethics approval <input type="checkbox"/> Group B – Excellent. Excellent and original approach to the research project; additional requirements either: (1) purely administrative e.g. ethics approval or (2) indicative of inexperience e.g. rescaling of project because it is too ambitious <input type="checkbox"/> Group C - Very Good. Solid performance with respect to of the Confirmation of Candidature but demonstrating less flair and originality than Groups A or B; additional requirements either: (1) purely administrative e.g. ethics approval or (2) indicative of inexperience e.g. rescaling of project because it is too ambitious <input type="checkbox"/> Group D – Good. Variable performance which on balance is of an appropriate standard; additional skills required e.g. ESL, statistics; and/or Confirmation of Candidature has been delayed > 8 months FTE without substantive reason(s) and permissions
<input type="checkbox"/> Recommendation CCR. Reconsideration of Confirmation of Candidature within six months of the initial presentation, subject to work undertaken to the satisfaction of the Higher Degrees by Research Sub-Committee. A second seminar presentation may be specified.	<input type="checkbox"/> Group E Proposed research not of sufficient scope for Research Masters or unrealistic in terms of resources and timeframe; candidate apparently has required skills; situation potentially redeemable within 6 months <input type="checkbox"/> Group F Proposed research suitable for Research Masters but candidate deficient in essential skills; situation potentially redeemable within 6 months
<input type="checkbox"/> Recommendation CCF. The candidate be asked to show cause why his or her candidature should not be terminated.	<input type="checkbox"/> Group G Candidate appears not to have skills necessary for research higher degree candidature and is unlikely to gain such skills within 6 months; this assessment must be checked with viva conducted by person with appropriate expertise independent of supervisory team; subject to result of viva HDRSC will ask candidate to show cause why his or her candidature should not be terminated. HDRSC may recommend candidate change enrolment to coursework masters, graduate diploma, graduate certificate.

Recommendation of the Supervisory Committee
DO NOT SUBMIT THIS FORM IF PROVISIONAL CANDIDATURE IS TO BE EXTENDED

Candidate's name J. DAISY MOSAPELO

Confirmation of Ph.D. candidature confirmed on 12-4-2011
(Name of degree) (Date)

Upgrade of candidature No Yes If yes,
Domestic student: A PhD assessment form must be completed by the Head of School and attached for approval by the Board of Higher Degrees by Research Committee.
International student: A PhD application form must be lodged with the International Student Centre prior to commencing the Confirmation of Candidature process.

Confirmation of Candidature subject to additional work specified below*:
.....

*The Graduate Research School must be notified when the work has been completed.

Additional comments especially on 1) needs for skills development by student and/or 2) additional funding / Infrastructure
.....

Confirmation of candidature is not approved, independent viva required.

Section 6. Signatures

Supervisory Committee Members (Please print name)	Signature	Date
Research Student Monitor <u>S. QAIR</u>	[Redacted]	<u>12.4.11</u>
Principal Supervisor <u>K. USHER</u>	[Redacted]	<u>12.04.11</u>
Co-supervisor <u>J. MILLS</u>	[Redacted]	<u>18/4/11</u>
Head of Discipline	[Redacted]	
Head of School <u>D. LINDSBAY</u>	[See attached]	
Candidate to confirm: I have met with my Supervisory Committee and have discussed and understand the outcomes of my confirmation of candidature seminar.	Name: <u>J. MOSAPELO</u> Signature: [Redacted]	<u>12.04.11</u>

Statistical design checked and approved by University Statistician Yes No Not applicable
Ethics approval obtained Yes No Not applicable
Note: Candidature will be confirmed after the statistical design has been approved and ethics approval has been granted.

Executive action by the Dean of Graduate Research Studies Yes No (to be considered by HDRSC)
Recommendation of Supervisory Committee approved Yes No (Supervisor interview required)

Signature, Dean of Graduate Research Studies.....
date

Additional comments for candidate.....

Recommendation of the Supervisory Committee
DO NOT SUBMIT THIS FORM IF PROVISIONAL CANDIDATURE IS TO BE EXTENDED

Candidate's name J. DAISY MEZAPALO

Confirmation of PhD candidature confirmed on 12-4-2011
 (Name of degree) (Date)

Upgrade of candidature No Yes If yes,
 Domestic student: A PhD assessment form must be completed by the Head of School and attached for approval by the Board of Higher Degrees by Research Committee.
 International student: A PhD application form must be lodged with the International Student Centre prior to commencing the Confirmation of Candidature process.

Confirmation of Candidature subject to additional work specified below*:

.....

*The Graduate Research School must be notified when the work has been completed.

Additional comments especially on 1) needs for skills development by student and/or 2) additional funding / infrastructure

.....

Confirmation of candidature is not approved, independent viva required.

Section 6. Signatures

Supervisory Committee Members (Please print name)	Signature	Date
Research Student Monitor <u>S. GAIR</u>	[Redacted]	
Principal Supervisor <u>K. USHER</u>	[Redacted]	<u>12.04.11</u>
Co-supervisor <u>J. MILLS</u>		
Head of Discipline	[Redacted]	
Head of School <u>D. LINDGAY</u>	[Redacted]	<u>12.04.11</u>
Candidate to confirm: I have met with my Supervisory Committee and have discussed and understand the outcomes of my confirmation of candidature seminar.	Name <u>J. MEZAPALO</u> Signature [Redacted]	<u>12.04.11</u>

Statistical design checked and approved by University Statistician Yes No Not applicable
 Ethics approval obtained 44221 Yes No Not applicable
 Note: Candidature will be confirmed after the statistical design has been approved and ethics approval has been granted.

Executive action by the Dean of Graduate Research Studies Yes No (to be considered by HDRSC)
 Recommendation of Supervisory Committee approved Yes No (Supervisor interview required)

Signature, Dean of Graduate Research Studies..... [Redacted] 09.10.12
 date

Additional comments for candidate.....

Quality Assurance of Confirmation of Candidature Proposal

Candidate: Daisy Mojapelo
School: Nursing Midwifery & Nutrition
Short Title of Thesis: The lived experiences of nurses in community home based palliative care in Botswana
Principal Supervisor: Prof K Usher, Dr J Mills

Date of Confirmation Seminar:

Project proposal submitted to the Research Education Sub-Committee:

Date Submitted: 4 October 2012

Degree: PhD

Project Proposal checked: Brian Lewthwaite

The Project involves mostly: Qualitative techniques Quantitative techniques

Is the methodology proposed for the study appropriate? Yes No See comment

Comments: It is most appropriate that a phenomenological approach be used in this study.

Recommendations: NA

Has the data collection process been documented adequately? Yes No See comment

Comments: Very good description and understanding of data sources and methods for collection.

Recommendations: NA

Proposed analytical techniques are satisfactory: Yes No N/A See comment

Comments:
Analysis procedures consistent with phenomenology methodology.

Recommendations: NA

All best Daisy with your research.

Proposal satisfactory from a perspective of design and analysis (tick alternative below):

Yes

No

Further written information is required

Please ask Student to make an appointment to see Professor Rhondda Jones

Date: October 6, 2012

Barbara Pannach, Project Officer, Graduate Research School

Appendix B: Ethics Approval



James Cook University

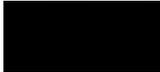
Townsville Qld. 4811 Australia

Tina Langford, Manager, Research Ethics & Grants

Research Services Ph: 47815011; Fax: 47815521

email: ethics@jcu.edu.au

Human Research Ethics Committee		Application ID
APPROVAL FOR RESEARCH OR TEACHING INVOLVING HUMAN SUBJECTS		H4221
PRINCIPAL INVESTIGATOR	Tshepiso Mojapelo	Student
SCHOOL	Nursing, Midwifery & Nutrition	
CO-INVESTIGATOR(S)		
SUPERVISOR(S)	Kim Usher and Jane Mills	
PROJECT TITLE	The Lived Experiences of Nurses executing Community Home Based Care for Palliative Care Patients in Botswana	
APPROVAL DATE:	23/11/2011	EXPIRY DATE: 30-Dec-13 CATEGORY: 1
<p>This project has been allocated Ethics Approval Number H4221, with the following conditions:</p> <ol style="list-style-type: none"> All subsequent records and correspondence relating to this project must refer to this number. That there is NO departure from the approved protocols unless prior approval has been sought from the Human Research Ethics Committee. The Principal Investigator must advise the responsible Human Ethics Advisor: <ul style="list-style-type: none"> periodically of the progress of the project, when the project is completed, suspended or prematurely terminated for any reason, within 48 hours of any adverse effects on participants, of any unforeseen events that might affect continued ethical acceptability of the project. In compliance with the National Health and Medical Research Council (NHMRC) "National Statement on Ethical Conduct in Human Research" (2007), it is MANDATORY that you provide an annual report on the progress and conduct of your project. This report must detail compliance with approvals granted and any unexpected events or serious adverse effects that may have occurred during the study. 		
Human Ethics Advisor :	Lindsay, David	
Email :	David.Lindsay@jcu.edu.au	
This project was Approved by Meeting on 29 Jun 2011		
Dr Anne Swinbourne <i>Chair, Human Research Ethics Committee</i>		

PRINCIPAL INVESTIGATOR	Tshepiso Mojapelo		Student
SCHOOL	Nursing, Midwifery & Nutrition		
CO-INVESTIGATOR(S)			
SUPERVISOR(S)	Kim Usher and Jane Mills		
PROJECT TITLE	The Lived Experiences of Nurses executing Community Home Based Care for Palliative Care Patients in Botswana		
APPROVAL DATE:	23/11/2011	EXPIRY DATE:	30-Dec-13 CATEGORY: 1
<p>This project has been allocated Ethics Approval Number H4221, with the following conditions:</p> <ol style="list-style-type: none"> All subsequent records and correspondence relating to this project must refer to this number. That there is NO departure from the approved protocols unless prior approval has been sought from the Human Research Ethics Committee. The Principal Investigator must advise the responsible Human Ethics Advisor: <ul style="list-style-type: none"> periodically of the progress of the project, when the project is completed, suspended or prematurely terminated for any reason, within 48 hours of any adverse effects on participants, of any unforeseen events that might affect continued ethical acceptability of the project. In compliance with the National Health and Medical Research Council (NHMRC) "National Statement on Ethical Conduct in Human Research" (2007), it is MANDATORY that you provide an annual report on the progress and conduct of your project. This report must detail compliance with approvals granted and any unexpected events or serious adverse effects that may have occurred during the study. 			
Human Ethics Advisor :	Lindsay, David		
Email :	David.Lindsay@jcu.edu.au		
This project was Approved by Meeting on 29 Jun 2011			
Dr Anne Swinbourne Chair, Human Research Ethics Committee			

Appendix C: Letter of Request to Botswana MoH to Conduct Study

Yuendumu Health Centre
P.O.Box 721
Via Alice Springs
0870
Northern Territory
Australia
18/04/11

The Director
Health Research Unit
Ministry of Health
P. Bag 0038
Botswana
Attention: P.Khulumani

Re: Request to conduct a study in Botswana:

Title: The lived experiences of Nurses providing Community Home Based Palliative Care to People Living with HIV/AIDS in Botswana.

Time frame: 31st March 2012 to 30th April 2012.

I write to request permission to conduct the above mentioned study as a requirement for my PhD. I am currently studying at James Cook University in Australia. I am a Botswana who resides in Australia as of 2006, and have worked for the Ministry of Health in Botswana AIDS department from 1999-2005.

The aim of this study will be to explore nurse's lived experiences in caring for PLWHAs from the 16 health districts that are on a community palliative care programme in Botswana. An interpretive phenomenological design will be employed as this will facilitate a more meaningful understanding of the experiences of the nurses. One nurse from each of the selected districts will be interviewed. The geographical locations and the size of the districts and population will be important criteria in selecting the districts. Furthermore, the districts will be identified from a representative range of the 26 districts and the magnitude of their operations. The rationale for the researcher to cover a wide area is that the researcher holds an assumption that there will be different responses from these areas.

Selected Districts

Gaborone City Council, Francistown City Council, Jwaneng Town Council, Orapa Mining Company, Kweneng East and West, Kgatleng, Ngwaketse District, Ngami, North East District, Kgalagadi, Tsabong, Gantsi, Central District i.e. Bobirwa Sub District and Serowe Palapye Sub District, Okavango Sub District.

It is my hope that the study findings will add onto the existing knowledge on executing palliative care in Botswana which is a new concept and practice. Preliminary results will be presented at the MoH and the Health Research Unit.

I also hope that the findings will make a significant contribution to the psychosocial programme of the Ministry of Health and improve staff job satisfaction.

I will take responsibility of sending request letters to the relevant districts authorities to request entry and conduct research using nursing staff. With the assistance of the District Health Team management, I will identify prospective participants. Protection

of staff in terms of confidentiality and right to participate will be verbally explained and a signed consent form will be obtained from the participants.

Thank you



Tshepiso Daisy Mojapelo

Cc: Dr. Lobelonyanya
Director: Department of HIV/AIDS Prevention (MoH)
P.S Makuruetsa
Community Home Based Care Coordinator
Department of HIV/AIDS Prevention (MoH).

Appendix D: Botswana MoH Application for Human Research Approval

Ministry of Health

Republic of Botswana

Application for Approval of Human Research

Section A: Instructions

1. For research/academic institutions or PHD students attach:
 - a) 14 copies of the Research Application form
 - b) 4 copies of the following:
 - i. Study proposal.
 - ii. Consent/authorization form or a request for waiver of consent/authorization- Setswana, English and back translation where applicable.
 - iii. Questionnaires to be used. Setswana, English and back translation where applicable.
 - iv. Curriculum vitae/ resume of each member of the Research team
 - v. Approval letter from other IRBs
 - vi. Grant approval letter
 - vii. Any other supporting materials i.e. recruitment scripts, brochures, flyers etc
2. For undergraduates and graduates attach one copy of the above listed items/ documents.

Section B: Application Details

1. Study Title: The lived experiences of nurses in community home based palliative care in Botswana	
2. Date of submission:	
3. Type of Research:	
i. Basic Science	()
ii. Public Health	(x)
iii. Clinical Research	()
iv. Human Biology	()
v. Other	

4. Principal Investigator(Name & Qualifications): Tshepiso Daisy Mojapelo MSc Nursing	4(i). Local Contact Details Name:
Postal Address: Nguu Clinic P.O Box 75 Bathurst Island, 0822, N.T, Australia	Postal Address:
Phone Number:+61400780922	Phone Number:
Email: Address: Tshepiso.mojapelo@my.jcu.edu.au	E mail Address:
Name of affiliate Institution/Organization: James Cook University	Name of Institution/Organization:
Department (If Government):	Department (If Government):

5. Other Investigators /Co-Principal Investigators			
Name:	Organization:	Email:	Telephone Number:

6. Key Personnel working with data that

may be linked to human subjects:

Name:	Organization:	Email:	Telephone Number:

Section C: Description of Research

Brief Description of Study

Palliative care is an emerging discipline with the majority of services so far delivered in developed countries. However, Webster, Lacey and Quine (2007) have suggested that HIV and cancer patients in developing countries would benefit from such a service. Harding et al (2005) observed that the high incidence of HIV/AIDS, co-morbidities and cancers in developing countries has led to the initiation of palliative care services in some countries. Despite the vast research conducted on HIV/AIDS in Botswana, little is known about the experiences and perceptions of community home based palliative care nurses. Palliative care in Botswana was started in 2003 as an initiative of the World Health Organization (WHO) to assist those countries with high HIV/AIDS prevalence rates to provide better care for People Living With AIDS (PLWHAs). The goal of the community home based palliative care initiative was to assist countries to develop better strategies for managing the pain and other debilitating symptoms associated with AIDS.

The purpose of the study is to explore the nurses' experience of delivering home based palliative care to PLWHAs and other chronic ill patients in Botswana. Data collection will be guided by the phenomenological approach outlined by van Manen (1990). Sixteen registered nurses from sixteen of the 26 health districts in Botswana will be included in the study. The districts will be selected according to their localities and geographical distances. An exhaustive process of data analysis will be undertaken to make sense of the meanings of the experiences. Data analysis will involve extracting significant statements from transcribed interviews, transforming the statements into clusters of meaning, and categorizing the statements into major themes that explain the phenomena.

This study will form and add to the growing body of research and knowledge related to HIV/AIDS in Botswana. Recommendations will be formulated from the findings of this paper for consideration by the Ministry of Health in Botswana so as to move forward and effectively respond to the challenges posed about palliative care approach for People Living with HIV/AIDS and other patients with chronic illnesses being cared for in the community in Botswana.

2. Rationale/Justification (*Why the need to carry out this study in Botswana*):

Caring for people in the home in Botswana is not a new concept, however due to HIV/AIDS epidemic, care has evolved to where community nurses, families, and volunteers struggle to manage patients with complex care needs effectively and, at times, in the absence of qualified health professionals. Most patients in the home struggle with pain because in Botswana due to the restricted supplies of opioids in the community (Makuruetsa et al. 2007). The readily available medications are paracetamol and ibuprofen; these drugs cannot effectively manage severe pain such as the pain experienced by people with conditions such as cancer. Despite the successful use of ARV in Botswana, there is limited evidence on the management of people in the community and the control of their pain and other symptoms. In many resource-constrained countries, AIDS has had a huge impact on nursing practices and on the role of health professionals in caring for the patients. For example, nurses are faced with many deaths, which often occur where the patient experiences severe and uncontrolled pain (Spence, Merriman and Binagwaho 2004, Struthers 2007). Despite this finding, there has been limited information in Botswana on the nurses' experiences and responses to the caring for HIV/AIDS in a palliative care situation at home. Given that, the number of PLWHAs and people living with chronic diseases is increasing in Botswana, the need for palliative care both in health settings and in the community is more important than ever before (Struthers 2007). Webster, Lacey and Quine (2007) demonstrated that palliative care and pain control has been extensively discussed in the available literature in developing countries which show less success stories in symptom management and pain. However, following an in-depth literature review in Botswana there is no specific literature found which outlines the experiences of nurses in community palliative care and pain management. In this regard, there is an urgent need to evaluate the nurses' experiences and responses to taking care of very ill patients in the community. When the experiences of the nurses are known, the information can be used to improve care delivery in the future and thus result in better outcomes for patients. .

3. Study Objectives (*Both General and Specific*):

Broad objective of the study

To investigate the experiences of Community Home Based Care palliative care nurses in Botswana.

Specific objectives

1.To establish the challenges faced by the nurses

2.To examine the support systems for the nurses

3.To determine the use of alternative therapies for pain and other debilitating symptoms

4.To offer recommendations for strengthening palliative care in Botswana specifically to pain management in the community

4. Expected Results (*Both Primary and Secondary endpoints*):

This is an academic research to meet the PhD requirements The expectation is that results will be utilized to develop data that will inform policy makers on the existing gaps in the palliative care strategy in Botswana.

Will develop evidence-based information on the nurses' views and experiences about the programme in order to correct and modify the existing gaps. As well as informing policy, makers and other key players on how to achieve optimum care of patients on palliative care at home.

Findings will also be used to develop recommendations for support strategies for nurses and others providing home based palliative care in Botswana.

criteria in selecting districts. The rationale to cover a wide area is that the researcher holds an assumption that there will be different responses from these areas.

6. Data Collection Methods (*Explain all procedures in detail*)

Participants will be asked an open-ended question. Tell me about your experience of caring for a patient who is on palliative care at home. Probing questions will be used to guide the interview. In phenomenology open-ended questions allow participant the maximum freedom to respond and provide a detailed description of their lived experiences. Interviews are expected to last between 45-60 minutes. In this study, interviews will be used as a means to explore and collect stories of the nurse's experiences to uncover a rich understanding of the nurses' experiences. Also to create an understanding between the researcher and the participants about the meaning of the experiences.

Interviews will be tape recorded with the participants' permission. The researcher will seek permission from the participants to use tapes and explain the purpose of tape recording. Participants will be assured of confidentiality and that tapes will be kept in a safe place. Interviews will be conducted at a place chosen by the participants in order to make them feel comfortable

The interviews will be conducted in English however participants will be free to clarify their stories in Setswana Each interview will be assigned a code and will be recorded on separate tapes. Tapes will be listened to after every interview, notes made immediately, and key words noted. The use of field notes will be useful to the researcher to capture all the information that may be missed and to retain data. These notes will be used in data analysis and interpretation.

7. Data Analysis (*Briefly explain how data will be analyzed*)

Data analysis will involve extracting significant statements from transcribed interviews and transforming the statements into clusters of meaning. The clusters will be categorized into themes giving the general description of the experiences and themes will become objects of reflection and interpretation.

8. Piloting/Pretesting (*Explain all procedures in details*) *No pilot testing will be done*

9. Protection of Subjects (*Describe measures to protect subjects from and minimize possible risk of harm, discomfort, or inconvenience*): Nurses will be told that if they feel uncomfortable to talk about their work situation they are free to withdraw from the study, stop the interview for a period of time, or seek support. Those nurses who will be participating in the study will be offered counseling services by the researcher who is a trained HIV/AIDS counselor or referred to a colleague. The names of participants will not be released and will be known only to the researcher. Resulting publications will use pseudonyms so the rights of the participants to privacy will be respected.

10. Approximate Date Study Recruitment will

begin: 01/05/2012

11. Estimated Duration of entire study:

01/06/2012

Section D. Methodology

1. Study Design

An interpretative phenomenological design will be employed, as this will facilitate the understanding of the experiences of the nurses. The study will be guided by one open-ended question followed by an in-depth probing.

Research question

What is the experience of nurses delivering community home based palliative care in Botswana?

Sub Questions

Has caring for PLWHAs who are terminally and chronically ill in the community changed the way nurses deliver their care

How does caring for patients at home affect nurses

What is the perception of nurses' effectiveness at managing pain and other debilitating symptoms for patients cared for at home.

Tell me about non conventional methods that nurses use or advise care givers to relieve pain and other debilitating symptoms in Botswana

Are there any other concerns you would like to discuss about palliative care in Botswana.

2. Study sites (Districts, Towns, Villages, Health facilities, Schools etc

Cities: Gaborone City Council, Francistown City Council,

Mining Towns: Orapa Mining Town, Jwaneng Mining Town, Selibe Phikwe

Districts: Ngwaketse, Kgatleng, North East, Gantsi, Tsabong, Ngami,

Sub districts: Kweneg West, Kweneng East, Bobirwa, Serowe/ Palapye, Okavango

3. Subject Population(s) (Clinical condition, Gender, age, and other relevant Characteristics):

This study is going to involve nurses who are working in the home based care programmed and one nurse will be identified from the 16 participating districts.

4. Sample size (The number of subjects to be involved in the study and how these subjects will be selected from the population):

Sixteen nurses will be interviewed. Purposive sampling will be done purposive sampling is the most non-probability sampling when identifying participants able to provide rich data. Experienced community home based care nurses will be invited to participant in this study. From the 26 health districts, participants will be selected from the 16 selected districts. One nurse from each participating district. The geographical locations the size of the districts and the population they serve will be an important criteria in selecting the districts. The districts will be identified from a representative range of districts and their magnitude of operations. The rationale to cover a wide area is based on the researcher's assumption that there will be different responses from these areas. In phenomenology, 10 participants are recommended however, Sandelwoski (1986) argue that researchers may continue to engage in an interview with participants until they believe there is no new information being received.

The researcher will write to the administration of each participating district explaining the purpose of the proposed study and requesting their support in recruiting participants. Invitation letters will be distributed to the nurses the letter will include the researchers name and contact details. Potential participants will be referred to the researcher for further information if required. Once recruited the researcher will provide the participants with an explanatory statement and a written consent to sign.

5. Subject Recruitment/Sampling Methods (Explain all procedures in detail):

The researcher will write letters to the Ministry of health requesting permission to conduct the study from the 16 selected districts with an explanation of the purpose of the study. Then letters will be sent to the district administration authorities requesting permission and release of the nurses. If permission is, granted invitation letters will be distributed to the community nurses employed in the district. The invitation letter will include the researcher's name and contact details. Potential candidates will be asked to contact the researcher by email for further information if they are interested in being interviewed. Once contacted the researcher will provide an explanatory statement and written consent to sign and return. There are 26 health districts in Botswana, therefore, 16 registered nurses will be invited and one from each of the participating districts. The districts will be identified from a representative range of districts and the magnitude of their operations. The geographical locations, the size of the district and populations they serve will be important

Appendix E: Botswana MoH Research Approval

TELEPHONE: 363 2766
FAX: 391 0647
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



Republic of Botswana

MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REF NO: PPME-13/18/1 Vol VII (401)

12 April 2012

Health Research and Development Division

Ms Tshepiso Daisy Mojapelo
Ngulu Clinic
P.O. Box 75
Bathurst Island
0822 N.T. Australia

Protocol Title: **THE LIVED EXPERIENCES OF NURSES IN COMMUNITY HOME BASED PALLIATIVE CARE IN BOTSWANA**

HRDC Approval Date:	10 April 2012
HRDC Expiration Date:	9 April 2013
HRDC Review Type:	HRDC reviewed
HRDC Review Determination:	Approved
Risk Determination:	Minimal risk

Dear Ms Mojapelo

Thank you for submitting application for the above referenced study. The study has been reviewed and approved for a period one year with effect from 10 April 2012.

This permit does not however give you authority to collect data from the selected sites without prior approval from the management. Consent from the identified individuals should be obtained at all times.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal must be submitted to the Health Research and Development Division in the Ministry of Health for consideration and approval.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Copies should also be submitted to all other relevant authorities.

Appendix F: Botswanan Study Approval

TELEPHONE: 363 2766
FAX: 391 0647
TELEGRAMS: RABONGAKA
TELEX: 2818 CARE BD



Republic of Botswana

MINISTRY OF HEALTH
PRIVATE BAG 0038
GABORONE

REF NO: PPME-13/18/1 Vol VII (401)

12 April 2012

Health Research and Development Division

Ms Tshepiso Daisy Mojapelo
Ngulu Clinic
P.O. Box 75
Bathurst Island
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Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research, Ministry of Health within 3 months of completion of the study. Copies should also be submitted to all other relevant authorities.

If you have any questions please do not hesitate to contact Mr. P. Khulumani at pkhulumani@gov.bw, Tel +267-3914467 or Lemphi Moremi at amoremi@gov.bw or Tel: +267-3632464

Continuing Review

In order to continue work on this study (including data analysis) beyond the expiry date, submit a Continuing Review Form for Approval at least three (3) months prior to the protocol's expiration date. The Continuing Review Form can be obtained from the Health Research Division Office (HRDD), Office No. 9A 10 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw As a courtesy, the HRDD will send you a reminder email about eight (8) weeks before the lapse date, but failure to receive it does not affect your responsibility to submit a timely Continuing Report form.

Amendments

During the approval period, if you propose any change to the protocol such as its funding source, recruiting materials, or consent documents, you must seek HRDC approval before implementing it. Please summarize the proposed change and the rationale for it in the amendment form available from the Health Research Division Office (HRDD), Office No. 9A 11 or Ministry of Health website: www.moh.gov.bw or can be requested via e-mail from Mr. Kgomotso Motlhanka, e-mail address: kgmmotlhanka@gov.bw . In addition submit three copies of an updated version of your original protocol application showing all proposed changes in bold or "track changes".

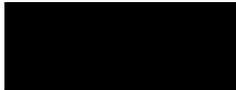
Reporting

Other events which must be reported promptly in writing to the HRDC include:

- Suspension or termination of the protocol by you or the grantor
- Unexpected problems involving risk to subjects or others
- Adverse events, including unanticipated or anticipated but severe physical harm to subjects.

Thank you for your cooperation and your commitment to the protection of human subjects in research.

Yours sincerely



P. Khulumani
For Permanent Secretary



Vision: *A Model of Excellence in Quality Health Services.*
Values: *Botho, Equity, Timeliness, Customer Focus, Teamwork.*



Appendix G: Botswana CHBC Application for Entry to Sites

Julanimawa Health Centre

P.O.Box 75

Bathurst Island

0822

Northern Territory

Australia

23/01/2012

To the Director

AIDS Department

Ministry of Health

P/Bag 0038

Botswana

Attention: CHBC Coordinator: Mrs. P. Makuruetsa

Re: Request for arrangement for entry into the selected districts for Data Collection

I kindly request your office to assist with facilitating my visit to the following districts for data collection from the 2nd of April to the 29th April 2012. Could you kindly communicate with the districts and forward the attached dates of visit. Gaborone, Kweneng East and West, Kgatleng, Jwaneng, Serowe Palapye, Boteti, Gantsi, North West, Okavango, Selibe Phikwe, Ngwaketse, North Eat, Francistown, Mabutsane. Due to logistical reasons for entry into Orapa I have replaced it with Boteti Sub District and I have replaced Tsabong with Mabutsane.

Attached is the schedule of intended dates and times of visit

Thank you

Yours Sincerely



Tshepiso Daisy Mojapelo

Appendix H: Information Sheet

INFORMATION SHEET

PROJECT TITLE: The Lived Experiences of Nurses delivering Community Based Palliative Care for people living with HIV/AIDS in Botswana.

You are invited to take part in a research project about the experiences of nurses delivering community based palliative care in Botswana. Given that the number of people living with HIV/AIDS (PLWHAs) is increasing and more people live with chronic illnesses in Botswana, nurses are a major source of health care for these people in the community. The aim of this study is to investigate the experiences and perceptions of community based palliative care nurses in the delivery of care to people with HIV/AIDS in Botswana. The study is being conducted by Tshepiso Daisy Mojapelo, PhD candidate in the School of Nursing, Midwifery and Nutrition, at James Cook University, under the supervision of Professor Kim Usher and Dr Jane Mills. The study will contribute to a PhD at James Cook University.

If you agree to participate in the study, you will be invited to be interviewed. The interview, with your consent, will be audio-taped, and should only take approximately 45 minutes to 1 hour of your time. Following the interview the audio tape will be transcribed verbatim for analysis. The interview will be conducted at your district, and at a venue of your choice. There is only one question that will be asked followed by a series of probing questions.

The main research question is:

What is the experience of nurses delivering Community Home Based Palliative Care Programs to PLWHAs in Botswana?

Sub-questions:

- Has caring for PLWHAs in the community changed the way nurses deliver their care in Botswana?
- How does caring for patients at home affect the nurses?

- What is the perception of nurses of their effectiveness at managing pain and other symptoms associated with HIV/AIDS when using a palliative care approach in Botswana?
- Are there any other concerns you would like to discuss about palliative care in Botswana?

The interview will be conducted in English however, for further clarification and if desired, you will also be able to make use of local language since the researcher is from Botswana.

Taking part in this study is voluntary and you can stop taking part in the study at any time without explanation or prejudice. You may also withdraw any unprocessed data from the study.

As some patients who are under your care might have had sad situations or stories they have shared with you it is possible that you may find some of the questions a little distressing. Extensive probing may also make you feel a bit emotional. If you do feel upset or distressed in any way, please advise the researcher and you will be referred to someone who can help you. In discussing HIV/AIDS related emotions the researcher can also offer assistance as she is an HIV/AIDS trained counsellor and has practised in Botswana.

Your responses and contact details will be strictly confidential. The data from the study will be used in research publications and reports to James Cook University and the Ministry of Health Botswana but all efforts will be taken to ensure you are not identified in any way in these publications.

If you have any questions about the study, please contact **(Principal Investigator and Supervisor)**.

Principal Investigator:

Tshepiso Daisy Mojapelo

School of Nursing, Midwifery and Nutrition

Supervisor: Details:

Name: Professor Kim Usher

School of Nursing, Midwifery and Nutrition

James Cook University

Phone:07 40421391

Mobile: 04000780922

Email: tshepiso.mojapelo@my.jcu.edu.au

James Cook University

Phone: 07 40421391

Mobile:

Email: kim.usher@jcu.edu.au

Co-Supervisor: Details

Name: Dr. Jane Mills

School of Nursing, Midwifery and Nutrition

James Cook University

Phone:07 40421548

Mobile: 0457525990

Email: jane.mills@jcu.edu.au

Counsellor: Details:

Name:Mable Kejelepula

AIDS Department Ministry of Health

P.Bag 0038 Gaborone

Botswana

Phone:+2673631524

mkejelepula@gov.bw

Principal Investigator: Tshepiso Daisy Mojapelo

Signature



Date: 26/11/2011

