CHAPTER ONE
ORIENTATION TO THE RESEARCH STUDY

1.1 INTRODUCTION AND BACKGROUND
In 2013, approximately 35 million people worldwide were living with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS); and Sub-Saharan Africa continues to be disproportionately affected by the global HIV burden with nearly 71 percent of People Living With HIV/AIDS (PLWHA) (The Joint United Nations programme on HIV/AIDS (UNAIDS), 2014: 26). Some countries in Sub-Saharan Africa are more affected than others. For example South Africa, one of the largest countries in Sub-Saharan Africa had an estimation of 6.1 million PLWHA in 2012, which accounted for 25 percent of all PLWHA in the region which is the highest in the world (National Department of Health, South Africa 2013: 4; UNAIDS, 2014: 26). Malawi, another Sub-Saharan Africa country and where this study was conducted ranked among the ten countries worldwide with a high HIV prevalence (Mwagomba, Zachariah, Massaquoi, Misindi, Manzi, Mandere, Bemelmans, Phillips, Kamoto, Schouten & Harries, 2010: 1). The 2010 statistics for Malawi, showed that out of a population of 15.4 million people, 1 million people were infected with HIV; and that HIV prevalence rate was higher in urban areas (17.1%) than in the rural areas (11.9%) (United States Agency for International Development (USAID), 2010: 1).

Different countries worldwide have responded to the HIV/AIDS epidemic through a range of approaches, including HIV counselling and testing, HIV prevention strategies for risk groups and strategies for prevention of mother-to-child transmission (PMTCT) of HIV but also provision of Antiretroviral Therapy (ART) for those infected (World Health Organization (WHO) Progress Report, 2009: 5). The provision of ART remains crucial to HIV/AIDS patients in order to prolong their lives and Sub-Saharan Africa had an estimated ART coverage of 44 percent in 2008 (WHO Progress Report, 2009: 5). Expanding access to ART contributed to a 19 percent decline in deaths of PLWHA in the region between 2004 and 2009 (UNAIDS Global Report, 2010: 8). Access to ART has led to the HIV infected people living longer and making the condition a chronic disease requiring palliative care throughout the disease trajectory as recommended by the (WHO), 2011: 1; Arnold & Liao, 2005: 1246).
According to UNAIDS Global Report (2010: 29), Botswana’s ART coverage exceeded 90 percent and the estimated annual number of AIDS-related deaths declined by half from 2002 to 2009, while the estimated number of children newly orphaned by AIDS reduced by 40 percent. ART in Kenya caused AIDS-related deaths to fall by 29 percent between 2002 and 2007; and in rural Malawi, provision of ART was linked to a 10 percent drop in the adult death rate between 2004 and 2008 (UNAIDS Global Report, 2010: 29). This has led to increase in number of HIV/AIDS patients who require care to promote their health and have quality productive lives since ART does not cure the condition.

The impact of HIV/AIDS epidemic has affected to varying degrees different health care systems around the world especially in developing countries that are already poorly resourced and financially constrained. In Malawi, the epidemic stretched an already fragile health care system beyond its capacity, with fifty percent of medical beds occupied by people suffering from HIV/AIDS leading to overcrowding and a further lack of resources in hospitals (National Statistical Office and ORC Macro, 2005b: 50; Ministry of Health (MoH), 2005a: 11). Due to the lack of resources in hospitals, and as recommended by AIDS Control Programme in 1995, the burden of care was shifted from the hospitals to the families and communities of PLWHA where locally available resources were used (Pindani, 2008: 6; Dippenaar, Chinula & Selaledi, 2011: 23). Subsequently, family members became the primary caregivers of the HIV/AIDS patients in their homes until end of life. In addition, statistics show that more females undertake the caregiver role than males worldwide (Stajduhar, Funk, Toye, Grande, Aoun & Todd, 2010: 573; UNAIDS, 2008: 2).

Within the context of HIV and AIDS, the home-based care strategy was recommended by WHO and UNAIDS to reduce the burden of HIV/AIDS care on the health care system and shift the burden to the patient homes in the care of family members (Bowie, Gondwe & Bowie, 2010: 370; Pindani, 2008: 6; Dippenaar et al., 2011: 23). The needs of the primary caregivers of HIV/AIDS patients are not adequately known. The needs of HIV/AIDS patients and palliative care nurses who care for them in the day clinics are also not known. Therefore this study explores the needs of HIV/AIDS patients, their primary caregivers and palliative care nurses and develops guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.
Malawi’s response to the HIV/AIDS challenge included the development and launching of the National HIV and AIDS Policy and the National HIV and AIDS Strategic Framework in the year 2000. The framework assisted in the provision of equitable treatment for PLWHA which significantly reduced the HIV and AIDS related mortality in Malawi (Nyirenda, Makwiza, Bongololo & Theobald, 2006: 69). In 2001, the Malawi National AIDS Commission (NAC) developed strategies to provide Community Home-Based Care (CHBC) services for HIV and AIDS patients, as advocated and recommended by WHO and UNAIDS in the year 2000 (Bowie et al., 2010: 370; Pindani, 2008: 6). Following the recommendation by WHO (2011) to include palliative care as part of HIV/AIDS management, even with the success ART, different countries included it as part of home-based and hospital care for HIV/AIDS patients. Palliative care was initially provided as an end of life care for terminal diseases such as cancer but has been advocated and noted to influence successful outcome of HIV/AIDS treatment in the face of ART where HIV/AIDS patients have increased their life expectancy (Jameson, 2007: 852).

Palliative care in Malawi was initiated as part of HIV/AIDS management in 2002 with nurses being the main providers at the clinics of selected government hospitals, some private hospitals and non-governmental organizations (NGO); home-based care was the main model of delivery for continuity of care (MoH, 2008: 3). The roles of palliative care nurses include physical, social, psychological and spiritual care but also supporting the family members to provide holistic care for the patient (MoH, 2008: 9). It is critical to involve the primary caregivers for holistic care to be achieved in the Home-Based Care (HBC) model (MoH, 2011a: 11).

The HBC model of palliative care delivery has proved to be cost effective as it allows for community participation and shared responsibility whilst the hospitals refer the HIV/AIDS patients home for long term care (Chinula, 2008: 3). This has also assisted the Malawi government to share its care responsibility with the communities and family members of HIV/AIDS patients (Pindani, 2008: 145). As such, HBC has become a more financial sustainable model in Malawi (Chinula, 2008: 3). This approach is also recommended by the African Palliative Care Association (APCA) (2008: 73) which states that HBC is one of the models through which effective and comprehensive palliative care can be delivered to HIV/AIDS patients and their families. However, effective HBC requires the support of nurses for family members to deliver the required care.
In the study conducted by Hudson, Quin, Kristjanston, Thomas, Braithwaite, Fisher & Cockayne (2008: 270), it was found that primary caregivers experience negative physical and psychosocial outcomes leading to burnout, fragmented care and a failure to cope with demands of the illness. These challenges were also found in a study conducted by Chinula (2008: 178) in Malawi where caregivers attributed these challenges to lack of support from health care workers in their caring role. This could cause a risk to the health of the patient, the wellbeing of the primary caregiver and overall health of the home environment. It is therefore vital that primary caregivers receive support from health care workers to be able to provide the required care and promote the health of HIV/AIDS patients.

Palliative care clinic nurses in Malawi do provide important care for HIV/AIDS patients and visit some patients in their homes but most of the care is provided in the home environment by family members. Worldwide, family members represent the backbone of health as they play the most prominent role in taking care of the sick at home as primary care givers, and in effect reduce overcrowding of patients with chronic conditions in hospitals (Stajduhar et al., 2010: 573). In Canada, it is estimated that family caregivers provide 80–90 percent of all care provided to individuals with different chronic conditions in the home settings (Stajduhar et al. 2010: 573). Family caregivers play a critical role and undertake complex care tasks including symptom assessment and management, hygiene care and medication administration (Hudson et al., 2008: 270). In addition APCA (2008: 73) noted that many households affected by HIV/AIDS in Sub-Sahara Africa have women and girls disproportionately affected by caregiver role and noted a gap in care giver support interventions. In agreement, Dippenaar et al., (2011: 27) found that most family carers for the sick were women and girls who lacked skills and knowledge and needed support from health care professionals in their role.

Furthermore, Hudson, Trauer, Graham, Grande, Ewing, Payne, Stajdunar & Thomas (2010: 656) recommended that support for family caregivers is a core function of palliative care and serves to improve the quality of life for patients as well as for their families. Stajduhar et al. (2010: 585) supported this notion in their study when they indicated that for important features of care to be identified and addressed, there is need for health staff availability, accessibility and support. This suggests a partnership between family caregivers and professional health staff. In addition, Hudson and Payne (2011: 865) asserted that it is the nurses’ role to ensure that the required care is provided to the patient through the exchange of
information and provision of required resources, which would support the primary caregiver to provide care to HIV/AIDS patients in the home.

The studies discussed above contribute significant knowledge on aspects of HIV/AIDS patients, palliative care and primary care givers. However, there remains a lack of information on support needs of primary caregivers in Malawi, an area which needs to be further investigated and addressed.

1.2 PROBLEM STATEMENT

As already noted, there is a great need to provide primary caregivers with adequate support as a means of ensuring positive outcomes for the patients and their families. However, there are no guidelines for nurses to support primary care givers of HIV/AIDS patients in palliative care in Malawi. Several researchers have reported that a lack of support from health care workers could contribute to negative physical and psychosocial outcomes in the caregivers (Hudson et al., 2008: 270; Dippenaar et al., 2011: 29). In addition, the Malawi National Palliative Care guidelines have indicated that carers should be supported through supervision and training to know how to provide care, yet no guidelines have been set on the provision of such support to the caregiver (MoH, 2011a: 6 - 7). The Malawi community home-based care guidelines focus on care of the patient and lack guidance on support to caregivers (MoH, 2005b: 87). It is clear that there is a gap between the needs of primary caregivers and support from nurses which could negatively affect the health of HIV/AIDS patients.

Although Hudson et al., (2010: 865) asserted that it is the nurse’s role to ensure that the required care is provided to the patient through support of the caregiver, little effort has been made to address support of primary caregivers in Malawi. Palliative care nurses work closely with patients to ensure that quality care is delivered but there is a need to include primary care givers who care for the patient in the nurses’ absence. Furthermore, since the introduction of palliative care in HIV and AIDS management, limited research has been conducted on the needs of primary caregivers in HIV and palliative care in Malawi, the needs of HIV/AIDS patients and the needs of palliative care nurses (Dippenaar et al., 2011: 28). In addition, Malawi documents show that there is no policy statement on palliative care and support of primary caregivers which could affect care in this area (MoH, 2011a: 7).
A study to explore and describe needs of primary caregivers, HIV/AIDS patients and the palliative care nurses according to their own self reports is important to highlight their needs and develop guidelines to support primary caregivers and promote the health of HIV/AIDS patients. This study therefore seeks to address a gap in the current body of knowledge and practice and intends to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.

1.3 RESEARCH QUESTIONS
From the above problem statement, the following research questions arose which provided a guide to the overall plan of the research:

- What are the needs of primary caregivers in relation to the care they give to HIV/AIDS patients?
- What are the palliative care needs of HIV/AIDS patients in relation to care they receive from primary care givers?
- What are the needs of palliative care nurses in relation to supporting primary caregivers of HIV/AIDS patients?
- What support do the primary caregivers need in caring for HIV/AIDS patients?
- What evidence exists in literature regarding support to primary caregivers of HIV/AIDS patients in palliative care?
- What are the guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care?

1.4 RESEARCH PURPOSE
The purpose of this study was to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.

1.5 OBJECTIVES OF THE STUDY
To achieve the purpose of the study, the researcher formulated the following specific objectives in three phases:

Phase One: Situational analysis

The objectives of the situational analysis in phase one was to:

1.5.1 Explore and describe the needs of primary caregivers in relation to the care they give to HIV/AIDS patients.
1.5.2 Explore and describe the palliative care needs of HIV/AIDS patients in relation to care received from primary caregivers.

1.5.3 Explore and describe the needs of palliative care nurses in relation to supporting primary caregivers of HIV/AIDS patients.

1.5.4 Explore and describe the support needed by primary caregivers in caring for HIV/AIDS patients.

**Phase Two: Integrative literature review**

The aim of the integrative literature review conducted in phase two was to:

1.5.4 Synthesize existing evidence regarding ‘support’ to primary caregivers of HIV/AIDS patients in palliative care through an integrative literature review.

**Phase Three: Guidelines development, description and evaluation**

The objectives of guidelines development, description and evaluation in this phase were to:

1.5.5 Develop, describe and evaluate guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.

**1.6 MOTIVATION FOR THE STUDY**

The researcher first developed interest in support as an area for research five years ago when she participated in a palliative care clinical orientation at a certain government hospital. The researcher came into contact with patients who had different chronic conditions including HIV/AIDS. The researcher witnessed how the patients and the primary caregivers of other chronic conditions were supported by the nurses through information and what to do at home. The medications were explained to both the patient and primary caregiver in detail. In contrast, the nurses from the same clinic demonstrated less care and support for patients with HIV/AIDS. The primary caregivers of HIV/AIDS patients were not told anything about the patients’ needs at home and how they could assist. They were only told to be careful while caring for their relatives by wearing gloves and very little or no information was given to the primary caregivers of HIV/AIDS patients concerning the provision of adequate care at home. Consequently, many HIV/AIDS patients had to come to the hospital more frequently, and often for care that should have been
manageable at home. This picture stirred the interest of the researcher to find ways of supporting primary caregivers of HIV/AIDS patients to promote their health.

For example, at one time a patient came from home to the clinic with severe leg pains and could not walk on his own. The patient had brought with him his bottle of morphine syrup, which he had received at the same clinic. The primary caregiver for this patient confessed that she did not know how to help the patient since she was not given any information on the patients’ condition and medications at the clinic and she felt that the pain was too much for the patient for her to give the morphine syrup. The researcher had done a palliative care course and understood that HIV/AIDS patients face different needs and their primary caregivers are failing to assist them due to lack of support from nurses. This scenario also stirred the interest of the researcher to find ways of supporting primary caregivers of HIV/AIDS patients to promote their health.

While involved in clinical teaching of students at a specific hospital, the researcher observed that hospital staff rarely, if ever engage with guardians or primary caregivers of patients. However, the primary caregivers were involved in feeding their patients, bathing them, taking them to the toilet or bringing a bedpan to them while in hospital. This motivated the researcher to develop guidelines for nurses to support the primary caregivers of HIV/AIDS patients in palliative care.

The researcher believes that the use of guidelines by nurses to support primary caregivers in the clinical area would promote the health of HIV/AIDS patients by meeting needs of the primary caregivers. The developing of support guidelines would also strengthen the performance of the health care system in order to achieve equity and quality of HIV/AIDS care as recommended by MoH (2010: ii) in their Health Sector Strategic Plan. The guidelines would also ensure that evidence based practice and the targeted care of HIV/AIDS patients on a palliative care programme is achieved.

1.7 SIGNIFICANCE OF THE STUDY
The researcher did not find written guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi although there is literature on the need to support primary care givers of HIV/AIDS patients and existence of general palliative care guidelines. This study is therefore the first of its kind in Malawi and the researcher believes that once guidelines are developed they would be used as
a guide, and this would hopefully result in uniformity and consistent support to primary caregivers of HIV/AIDS patients. As such, findings of this study could make a substantive contribution to strengthening the quality and equity of the health care systems in Malawi. The researcher also believes that results of the study could generate awareness and knowledge of the supportive needs of primary caregivers, needs of HIV/AIDS patients and needs of palliative care nurses. It would also significantly contribute to the body of knowledge by revealing the unmet needs which would help to inform and add to scholarly research in palliative care (Creswell, 2009: 107). Furthermore, it would also contribute to improvement of clinical practice in palliative care by assisting to improve quality care, decision making and the empowerment of primary caregivers, HIV/AIDS patients and palliative care nurses.

Limited research has been conducted in palliative care for HIV/AIDS patients, which includes primary caregivers in Malawi. This study could set the stage for future studies in palliative care in Malawi and contribute to palliative care research and share evidence-based practice knowledge in the country. In addition, the study would contribute to nursing education by providing an evidence base to inform the development of relevant training for health professionals and development of training materials in palliative care nursing. This research study may also persuade the Nurses and Midwives Council of Malawi (NMCM) to include palliative care training into its curriculum which is currently missing.

At present, there are no Malawian government policy documents pertaining to this area of palliative care. The recommendations from this research study could inform and influence policy-makers on the support needs of HIV/AIDS patients, their primary caregivers and needs of palliative care nurses. The study may also inform and assist palliative care management and clinical managers of different palliative care settings to look at improving services by supporting primary caregivers and developing appropriate information and education messages. The collaboration of all relevant stakeholders in this study would also give a strong foundation to the developed guidelines which could in turn encourage their adoption by Ministry of Health.

Finally, the developed guidelines could be adopted and implemented in other similar settings both locally and internationally. Locally, other specialities such as oncology, community, general nursing and midwifery could draw from the research and guidelines to better support their patients and primary caregivers. Other countries with similar resources could also draw ideas from the guidelines in this study.
1.8 DEFINITION OF CONCEPTS

The main concepts in this study are defined below:

**Palliative care:** Refers to an ‘approach which improves the quality of life of patients and their families facing life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement’ (Eyre, 2010: 43). In this study, the term refers to providing such care for HIV/AIDS patients and involving the primary caregivers through mobilization of information, clinical, psychosocial, spiritual and physical resources throughout the entire course of HIV/AIDS infection to achieve optimal quality of life and promote health.

**HIV/AIDS patients:** refers to people who have tested positive for Human Immune-deficiency Virus in their blood (Oxford Advanced Learners dictionary, 2005: 709). In this study it refers to people who are HIV positive. They could be on ART or not but receive palliative care services in the selected two districts in Malawi.

**Primary caregiver:** Is defined as a lay person in a close supportive role who shares in the illness experience of the patient and who undertake vital care work of the patient (Payne, Hudson, Grande, Oliviere, Tishelman & Pleschberger, 2010: 239). In this study, it refers to any person regardless of experience, knowledge and expertise, who is the main carer for HIV/AIDS patients in the home on daily basis. This person could be a family member, friend or neighbour of HIV/AIDS patients.

**Nurse:** refers to a person who is educated in the scientific basis of nursing under defined standards of education and is concerned with the diagnosis and treatment of human responses to actual or potential health problems (Stedman’s Medical Dictionary for Health professions and Nursing, 2008: 1088). In this study the term ‘nurse’ will include all categories of nurses who provide palliative care services to HIV/AIDS patients and are registered with the Nurses and Midwives Council of Malawi and permitted to practice.

**Guidelines:** Are defined as instructions that are developed and used to assist in making a decision or form an opinion (Oxford Advanced Learners Dictionary, 2005: 709). In this study it refers to instructions that
would assist in guiding decision-making and actions of nurses to support primary caregivers and HIV/AIDS patients in health care matters.

**Support:** Is defined as provision of nursing resources, supporting family members, friends and others whom the patient relies on including providing assistance to the patient (The Stedman’s Medical Dictionary for Health professions and Nursing, 2008: 1417) In this study it refers to physical, social, spiritual, provision of resources, information, emotional and mental support in relation to HIV/AIDS patients in palliative care.

**Needs:** Are defined as a drive and requisite necessary for human well-being when there is a gap between the state desired and the actual state of the person (O’Brien, 2010: 433 & 434). In this study it refers to need for knowledge and information required for decision making, resources and expertise to provide holistic care. It also refers to physical, psychosocial and spiritual needs in relation to care provision.

### 1.9 RESEARCH DESIGN AND METHODOLOGY

A qualitative research design which was explorative, descriptive and contextual in nature was utilized (Creswell, 2007: 39 - 40; Polit and Beck, 2008: 17 - 19; Yin, 2011: 11; Burns and Grove, 2007: 240) since support to primary caregivers is not common in the clinical nursing field and limited information exist on guidelines for nurses to support primary caregivers of HIV/AIDS patients in Malawi. A comprehensive discussion of methodology and justification is described in Chapter 2.

### 1.10 ORGANIZATION AND OUTLINE OF THE THESIS

**Chapter 1:** This chapter discussed the introduction, background and rationale of the study.
**Chapter 2:** This chapter has discussed the research design and methodology.
**Chapter 3:** This chapter presented findings of the study.
**Chapter 4:** This chapter is a discussion of the key research findings.
**Chapter 5:** This chapter has discussed an integrative literature review.
**Chapter 6:** This chapter has discussed the development and description of guidelines.
**Chapter 7:** This chapter has presented the conclusion, limitations and recommendations of the study.
1.11 SUMMARY
This chapter formed an introductory section of the thesis presenting the background, motivation and significance of the study. In addition, the chapter described the research problem and questions, purpose and objectives of the study. It also stated how the thesis would be organized.
CHAPTER TWO
RESEARCH DESIGN AND METHODOLOGY

2.1 INTRODUCTION
The previous chapter presented the overview, problem statement and background of the study. This chapter describes the methodology of this research study and has been divided into two main sections. The first section examines the qualitative paradigm that has been used in this study and its underpinnings and justification; this section also details the study design. The second section includes the data collection process, sampling and data collection methods, data analysis, trustworthiness and ethical considerations. This section also includes the role of the researcher and reasoning strategies used by the researcher throughout the research process.

The main purpose of this research study is to develop guidelines for palliative care nurses to assist them to provide primary caregivers of HIV/AIDS patients with support needed to ensure positive outcomes for both patients and caregivers. This main purpose is built upon the foundation of a needs assessment of HIV/AIDS patients and their primary caregivers and palliative care nurses with particular focus on support of primary caregivers of HIV/AIDS patients. This study adopted a qualitative approach that was designed in three phases to achieve the research objectives. The three phases are displayed schematically below, see figure 2.1:
2.2 RESEARCH DESIGN AND METHODS

A research design, according to Chinn and Kramer (2008: 270) outlines the procedure and contingencies used for answering research questions. Similarly, Fouche in De Vos, Strydom, Fouche and Delport, (2005: 268) define it as an approach the researcher selects or decisions in planning to study a particular phenomenon. In this study, research design followed a qualitative, descriptive and explorative approach that is contextual in nature.

2.2.1 A qualitative design

A qualitative approach provides an appropriate design for the study objectives to be met. This assertion is based on the fact that qualitative research approach is best able to answer questions about the complex, subjective, interpretive and at times intangible nature of the phenomena (i.e. support of primary caregivers) with the aim of describing and understanding the phenomena from the participants’ point of view and at the site where participants experienced the issue (Fouche & Delport in De Vos, Strydom, Fouche & Delport, 2011: 64 - 65). As such the researcher had to go to the natural setting where the phenomenon was experienced (Streubert & Carpenter, 2011: 27). A qualitative approach enabled the researcher to get to the inner experience of participants, and
determine how meanings are formed and interpreted rather than attempt to test variables as would occur in quantitative research (Corbin & Strauss, 2008: 12). A qualitative research design also assist in providing theoretical foundation for nursing interventions; guiding nursing practice and theory development (Streubert & Carpenter (2011: 19).

A qualitative research design assisted the researcher to explore and understand the meaning that individuals or groups ascribe to a problem (Creswell, 2009: 4). This assertion is made because the researcher was able to capture the meaning of real world events from the emic (participant’s) perspective as opposed to the etic (researcher’s) view (Yin, 2011: 11). A qualitative approach allowed the researcher’s relationship with participants to be one of the building blocks since more time was spent with them because of being a human instrument during data collection (Guba & Lincoln (2008: 266). It is also noted that the researcher had the opportunity to embed in multiple realities and commit to creating meaning for the individuals as a belief of qualitative researchers (Streubert & Carpenter, 2011: 20).

The above reasons demonstrate the appropriateness of a qualitative strategy for this study because the researcher described the phenomenon under study ‘support of primary caregivers of HIV/AIDS patients in palliative care’ in words and not numerically. This facilitated the researcher to discover new meanings and gain additional insight related to the phenomena under study which is the needs of primary caregivers, palliative care nurses and HIV/AIDS patients. Direct quotations of the participants were captured during data collection to reflect personal experiences. However, the researcher is by no means placing qualitative approach above quantitative approach but focused on its suitability to answer the research question.

The researcher’s qualitative research design incorporated a descriptive, explorative and contextual approach. These approaches offered depth and breadth leading to a greater understanding of the phenomenon as each research strategy contributed a different piece to the puzzle and offered another unique perspective on the phenomenon (Curtin & Fossey, 2007: 88).
2.2.2 A descriptive approach

A descriptive research approach was used to collect descriptive information on needs from individual HIV/AIDS patients, primary caregivers and palliative care nurses until data saturation was reached.

In a descriptive approach the researcher described groups, activities, situations or events with the focus on structure, attitudes or behaviour (Adler & Clark, 2011: 14). The descriptive nature of research is to present a picture of the specific detail and deeper meaning of a situation, social setting and relationship of the needs of HIV/AIDS patients, primary caregivers and palliative care nurses (Fouche & De Vos in De Vos, Strydom, Fouche & Delport, 2011: 96). A descriptive approach allowed participants to tell their stories and fully describe the phenomenon accurately. This in turn gave the researcher access to wealth of knowledge that would not be made available through other methods. Gibbs, Keally, Willis, Green, Welch & Daly (2007: 541 - 542) asserted that using a descriptive approach in isolation could provide a weak basis for practice or policy decisions because of possessing little explanatory power but ensured description of new important information about this phenomenon in this study.

This approach was supported by tenets of qualitative research and therefore, the choice of qualitative paradigm for this study. Palliative care research in this context is a new research area in Malawi particularly as it relates to primary caregivers, palliative care nurses and HIV/AIDS patients. As such a descriptive research approach was appropriate as it provided rich description of information from participants on the phenomenon. Based on these descriptions, guidelines were developed and described for nurses to support primary caregivers of HIV/AIDS patients. Using a descriptive approach ensured adequate overview of the setting, describing a range of experiences and provision of important new information (Gibbs et al., 2007: 541). The background of the whole context added meaning to the events that occurred. Therefore, objectives one, two, three, four and six of the study were achieved by use of descriptive study design because it specified what data to be collected.
2.2.3 The explorative approach

The explorative research approach was used to gain insight into the situation, phenomenon, community and individual when there was lack of basic information on a new area of interest and to get acquainted with the situation which are the needs of HIV/AIDS patients, primary care givers and palliative care nurses (Fouche & De Vos in De Vos, Strydom, Fouche & Delport, 2011: 95). According to Burns and Grove (2011: 8) an explorative approach should be used to assist the researcher in clarifying relationships among the phenomenon and identifying why certain events occur. The explorative approach aimed at exploring the dimensions to become familiar with the phenomenon. The explorative study could have modest implications for practice if used in isolation (Gibbs et al., 2007: 542). This approach was utilised by the researcher in order to shed light on various ways in which a phenomenon was manifested and its relationships (Polit & Beck, 2008: 21). Support of primary caregivers in palliative care for HIV/AIDS patients is a phenomenon that is not well understood. The researcher chose the explorative research approach to collect trustworthy qualitative data that could be described in the research findings; hence explorative design was also important in this study.

2.2.4 Contextuality

Contextuality is used where the goal is to explore and describe the phenomenon in the environment where it occurs (Nunes, Martins, Zhou, Alajamy & Al-Mamari, 2010: 82). This research study is contextual in nature as it aimed at investigating the phenomenon of needs of primary caregivers, needs of palliative care nurses and needs of HIV/AIDS patients in the two districts in Malawi in the environment where it occurs which gives this study a unique context. Therefore, the results were not fully reflective of the whole population of Malawi but a cross-section of it. The aim is to provide a dense description of the support needs of primary caregivers, needs of palliative care nurses and HIV/AIDS patients in Malawi in order to develop the guidelines. This aims at exploring an understanding which is unique and particular to the participants and not intended for generalizing of the findings.

2.3 THE STUDY SETTING

Qualitative researchers identify a setting where it is likely that data relevant to the problem would be readily available (Gibbs et al., 2007: 541). The research study was conducted in Lilongwe and
Salima districts of Malawi. A total of three settings were chosen from these two districts (two from Lilongwe and one from Salima districts). A brief description of Malawi and the health care delivery system is described below to provide the context of where the study was conducted.

Malawi is a landlocked country situated in the south-eastern part of Africa and lies between 13 57.5’ and 33 42’ within the Sub-Saharan region. It has a population of about 14.4 million people (National Statistical Office (NSO), (2009: i). It shares boundaries with Zambia in the west and northwest, the People’s Republic of Mozambique in the east, south and south-west and United Republic of Tanzania in the north and north east (see annexure A for the map of Malawi and bordering countries). The country is divided into three (3) administrative regions namely the northern, central and southern regions and has a total of 28 districts. Each district is further divided into traditional authorities, covering several villages. The village comprises the smallest administrative unit in the country (NSO 2011: 1).

This study was conducted in both rural and urban settings of Lilongwe and Salima districts in Malawi in order to obtain needs of participants from different locations, and with the view that needs could potentially be different between rural and urban settings. Lilongwe is the capital and largest city of Malawi, and the site for a range of different programs, including for HIV and AIDS implemented by the government and non-governmental organizations. The programmes include HIV Counseling and Testing (HCT), treatment including home-based care and palliative care. Kamuzu Central Hospital (KCH) and Nkhoma Hospital were the chosen sites in Lilongwe. KCH is a tertiary referral hospital for the Central region, although some referral cases are sent from other regions of the country. It has a bed capacity of 750; however, the number of patients typically exceeds the number of beds. It is a government hospital that provides services to a population of approximately five million people for free. The KCH palliative care clinic is one of the clinics at this hospital. It had 10 trained palliative care nurses of which six (6) were registered nurses and four (4) were enrolled nurses (Paseli, 2011: verbal). It is run as a day clinic but also accepts referred patients from different wards for palliative care. The KCH palliative care clinic attends to approximately 520 patients each quarter; most of these are referred cases from the out-patient department, ART clinic, different wards and some come straight from home while others come from other districts in the country.
The second site used for the study was Nkhoma Hospital, which is operated by Christian Health Association of Malawi (CHAM) and owned by the Church of Central Africa Presbyterian (CCAP). It is a 220 bed capacity hospital located within Lilongwe district, but is 50km from the city. Nkhoma Hospital is run like a district hospital; has 11 health centres; and also provides primary health care to a population of 60,000 and referral care to approximately 450,000. The hospital had 39 nurses and 30 clinical officers and services are provided at a fee. The hospital runs mobile clinics for children and pregnant women, and also offers home-based care services, eye care services, HIV/AIDS care, Nutritional rehabilitation care and palliative care services. The palliative care clinic at this hospital is run by nurses and currently it has five (5) trained palliative care nurses of which two (2) are registered nurses and three (3) are enrolled nurses (Chikuse, 2011: verbal). This clinic gets referral cases from the out-patient department, ART clinic, different wards and some patients who come straight from home. In 2011, this clinic had 179 adult male patients, 235 adult female patients and 56 children on the programme (Chikuse, 2011: verbal).

The third site used for the study was NdiMoyo palliative care centre in Salima district about 100km from Lilongwe district. Salima district has one district hospital that serves a population of 300,000 people. Ndimoyo palliative care centre is a non-governmental institution offering palliative care in the district and also to patients across the country. According to Finch (2008: 118) the centre receives referred patients from many places and districts across the country. In 2011, the centre had 350 registered patients (Finch, 2011: verbal. The centre is also a clinical placement site for training of health professionals after theoretical training through the Palliative Care Association of Malawi (PACAM) (Finch, 2008: 119). Ndimoyos’ interest is directed towards assisting those who are terminally ill with cancer, HIV/AIDS and/or other progressive and irreversible conditions. Ndimoyo palliative care clinic had five (5) palliative care nurses in which three (3) were professional nurses and two (2) were enrolled nurses (Finch, 2011: verbal).

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1 In Malawi clinical officers are mid-level health practitioners who undergo a three year diploma course in clinical medicine training at specific Malawian institutions followed by one year internship. They are qualified and licensed to perform general medicine duties such as diagnosis and treatment of diseases and injury, ordering and interpreting medical tests, performing routine medical and surgical procedures and referring patients to medical officers.
The researcher chose these three settings because they provide hospital and home-based palliative care in the respective catchment areas in the two districts. Although the sites are a distance apart in the two regions, they have been chosen because of the richness in potential participants of the study which the researcher was focusing on. The researcher chose these sites also to provide an overview of government; CHAM and NGO palliative care perspectives which are the palliative care providers in Malawi (see annexure A for the Districts of the study setting). These palliative care centres have nurses as the main providers and involve volunteers in different communities and families as primary care-givers in the home. These clinics serve as referral sites from ART clinics for patients in need of palliative care and also urban and semi urban communities of Lilongwe and Salima. The palliative care clinics are open Monday to Friday from 8am to 4pm and home-based palliative care is provided through home visitations. After hours, needed care is provided by hospitals for admitted patients or in the home by primary caregivers.

**Health Care Delivery System**

In Malawi, the health care delivery system is structured around Primary Health Care (PHC), which the government of Malawi endorsed as the main health service delivery strategy in order to ensure universal access to basic services and reduce social disparities (Chilemba, 2013: 41). The aim of PHC is to improve the health status of the population by focussing on an essential health care package that is cost-effective and accessible to the general population which is a basic human right (Muller, 2009: 88). Most of the health care services in Malawi are provided by three main agencies. These include the Malawi government’s Ministry of Health and Population and Ministry of Local Government (which provides 50 percent of services); Christian Health Association of Malawi (CHAM) (provides 40 percent of services) and private practitioners, commercial companies, armed forces and non-governmental organizations (NGOs) (provide 10% of health care services) (Department for International Development, 2008: 4). It is worth noting that services provided by the Ministry of Health and Ministry of Local Government are free of charge while those provided by CHAM and private practitioners are fee-based. The Malawi government has a service agreement with its various partners and reimburses the costs for other services provided by private institutions such as maternal health, child health, tuberculosis and antiretroviral treatment (Department for International Development, 2008: 12).
Provision of services in Malawi is divided into three levels namely: primary, secondary and tertiary. These different levels are linked to each other through an elaborate referral system that has been established within the health care system (MoH, 2011b: 83). The focus of interventions at the primary level is on preventive and basic curative services for uncomplicated conditions and is offered at clinics and health centres. District hospitals, community hospitals and some CHAM hospitals fall under the secondary level, and provide a range of preventive, curative and rehabilitative services but also receive referrals from primary level facilities. Tertiary level facilities are hospitals that provide similar services to district hospitals, but in addition provide specialist interventions and receive referrals from the secondary level. Tertiary health interventions are provided through the central hospitals and a few private hospitals. Palliative care clinics are located in some district hospitals and tertiary hospitals but also some private hospitals and NGOs. Some palliative care clinics provide only hospital-based palliative care; while others are provide both hospital and home-based palliative care.

2.4 POPULATION

The population in the study included 244 nurses of different categories working in the three palliative care clinics in the two districts, 1154 HIV/AIDS patients in the three palliative care clinics and 450 primary care givers of the HIV/AIDS patients in the three palliative care clinics (see table 2.1 below). The aim of this research influenced the researcher to select the population of HIV/AIDS patients, primary caregivers and palliative care nurses in their setting so that they provide information considered relevant to the research problem. The population included three hundred and thirty four (334) HIV/AIDS patients from KCH palliative care clinic, three hundred and fifty (350) HIV/AIDS patients from Ndimoyo palliative care clinic and four hundred and seventy (470) HIV/AIDS patients from Nkhoma palliative care clinic. The population for primary caregivers included thirty (30) from KCH palliative care clinic, three hundred (300) primary caregivers from Ndimoyo palliative care clinic and one hundred and twenty (120) primary caregivers from Nkhoma palliative care clinic. In addition, KCH had two hundred (200) nurses, Nkhoma hospital had 39 nurses and Ndimoyo palliative care clinic had five (5) nurses. The sample for this study was selected from this population which has been displayed in table 2.1 below:
Table 2.1: Population size from three study sites

<table>
<thead>
<tr>
<th>Population type</th>
<th>Ndimooyo</th>
<th>KCH</th>
<th>Nkhoma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary caregivers</td>
<td>300</td>
<td>30</td>
<td>120</td>
<td>450</td>
</tr>
<tr>
<td>HIV/AIDS patients</td>
<td>350</td>
<td>334</td>
<td>470</td>
<td>1154</td>
</tr>
<tr>
<td>Palliative care nurses</td>
<td>5</td>
<td>200</td>
<td>39</td>
<td>244</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>655</strong></td>
<td><strong>564</strong></td>
<td><strong>629</strong></td>
<td><strong>1848</strong></td>
</tr>
</tbody>
</table>

2.5 SAMPLING

The researcher selected participants using purposive sampling. In purposive sampling, the researcher selected the participants by setting a boundary on study participants and included only the population which was in contact with the phenomenon which is HIV/AIDS patients, their primary caregivers and nurses working in palliative care clinic at the three centres (Battaglia, 2011: 524). Draper and Swift (2011: 5) assert that the researcher in purposive sampling select people who are users of a particular service or clinic who are eligible and accessible in the population. In addition, purposive sampling requires that people be deliberately selected with an explicit purpose in mind, namely to address the research aim and because they are rich sources of data in relation to this (Teddile & Yu, 2007: 80 - 83; Tongco, 2007: 151). Purposive sampling ensured that participants who meet the inclusion criteria were recruited. It was also employed to recruit experts during development of guidelines.

2.5.1 Sample and sampling process

Sampling and data collection are critical to determining the quality of a study (Gibbs et al. 2007:540). In this study, participants were thus recruited after getting permission from the Ministry of Health and Population in Malawi, District Health Officers (DHO) of the respective districts, hospitals and palliative care clinic managers. In the sampling process the researcher had the opportunity to select a portion of HIV/AIDS patients, their primary caregivers and palliative care nurses as representative of the population to be studied. The researcher used her expert judgement in selecting participants that purposefully informed understandings on the purpose of the research (Creswell, 2007: 125). The researcher with the assistance of the nurses at each clinic selected HIV/AIDS patients who adhered to the sampling criteria to participate in the study. The HIV/AIDS
patients were approached during their utilization of palliative care services after being identified by the nurses for consent. The primary caregivers were selected with the assistance of the nurses and also after getting verbal and written consent from the HIV/AIDS patients. Nurses working in palliative care centres were selected using the staff register but also by checking with individual nurses for inclusion criteria. This study used a sample in three districts in Malawi, as such the findings are unique to that population and are not intended to be generalised to a larger population.

2.5.2 Sample size
Sample size plays an important role in research however in qualitative research data saturation determines sample size (Marshall, Cardon, Poddar & Fontenot, 2013: 12). As a characteristic of qualitative research, the researcher focussed on quality of information from what she wanted to know rather than on the size of the sample (Burns & Grove, 2011: 317). This ensured that the number of participants was adequate when saturation of information (the point at which no new information emerges from the data) was achieved (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles & Grimshaw, 2010: 1239). Saturation was decided by the researcher, supervisors and the independent coder who analysed the data.

The study included a sample of 51 participants from the three study sites. The sample included eighteen (18) primary caregivers from the three study sites, eighteen (18) HIV/AIDS patients from the three study sites and fifteen (15) palliative care nurses from the three study sites. The sample sizes from the three sites have been displayed in table 2.2 as follows:

**Table 2.2: Sample size from three study sites**

<table>
<thead>
<tr>
<th>Study site</th>
<th>Number of Primary caregivers</th>
<th>Number of Palliative care nurses</th>
<th>Number of HIV/AIDS Patients</th>
<th>Sub-total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ndimoyo</td>
<td>6</td>
<td>4</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>KCH</td>
<td>6</td>
<td>6</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Nkhoma</td>
<td>6</td>
<td>5</td>
<td>6</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>18</strong></td>
<td><strong>15</strong></td>
<td><strong>18</strong></td>
<td><strong>51</strong></td>
</tr>
</tbody>
</table>
People who met the following inclusion criteria which represented the sample required for the study were selected as participants:

**Inclusion Criteria for HIV/AIDS patients was that they were:**
- Aged 18 years and above
- On a palliative care programme for a minimum period of three months or more, so that they could give the information needed under study because of the services they get.
- Able to communicate in either English or Chichewa and be able to give written and verbal informed consent.
- Living within the geographical study sites of the two districts.
- Male and female gender.

**Inclusion Criteria for primary caregivers of HIV/AIDS patients were as follows:**
- The primary care givers of HIV/AIDS patients.
- Able to communicate in either English or Chichewa and be able to give written and verbal informed consent.
- Living within the geographical study sites with the patient.
- Primary caregiver for a minimum period of three months or more.
- Aged 18 years and above

**Inclusion Criteria for palliative care nurses was that they were:**
- Working as palliative care providers for at least three months, so that information was gathered from nurses experienced in working with HIV/AIDS patients.
- Willing to participate in the study and give verbal and written consent.
- Both genders of nurses were included.
- Either professional nurses or staff nurses

**2.5.3 Recruitment process**
Recruitment of study participants involved the actual process of seeking commitment from individuals who meet the inclusion criteria as participants. In the sampling process the researcher
had the opportunity to select a portion of HIV/AIDS patients, their primary caregivers and palliative care nurses as representative of the study population which the researcher was interested in. The researcher selected participants using purposive sampling so that individuals who can purposefully inform understandings on the purpose of the research were selected (Creswell, 2007:125). It should be noted that in this study, no incentives were offered during recruitment of participants. The following strategies were employed during recruitment of study participants:

The researcher was assisted by the nurses at each site to recruit HIV/AIDS patients who adhered to the sampling criteria. This was done because HIV/AIDS is still a sensitive topic to be discussed in Malawi, and some patients may not like to be directly approached by a researcher. This was also done to avoid unintentional HIV status disclosure during selection of the participants. After the clinic nurses approached the HIV/AIDS patients and they agreed to participate in the research that a meeting was arranged with the researcher. Nurses explained the study to each patient. The information leaflets were also provided to patients who could read. The HIV/AIDS patients were approached during their utilization of palliative care services after being identified by the nurses for consent.

The primary caregivers were again selected with the assistance of the nurses; but the researcher also sought verbal and written consent from the HIV/AIDS patients for whom they were providing care. Finally, nurses working in palliative care centres were selected using the staff register but also by checking with individual nurses for inclusion criteria. The researcher then established with the participants on convenient time, venue, and date to be interviewed. All participants chose to be interviewed at the clinics.

There were several challenges with the recruitment process in this study. The researcher made several fruitless visits to Nkhoma Hospital and some participants did not show up for one reason or the other. However, it was easy to access participants from NdiMoyo palliative care site and KCH palliative care clinic. It was also hard to get all focus group members from other sites together in time and several attempts had to be made before the group could be complete.
2.6 ROLE OF THE RESEARCHER IN THE PROCESS OF DATA COLLECTION

The quality of qualitative research relies on the researcher’s skills in obtaining information using the methods selected. In order to ensure the quality of data and data gathering processes, the researcher of this study was involved in the following roles:

2.6.1 Gaining Entry

Gaining access for the execution of a research study requires preparation and planning especially if access is required to organizations and institutions, such as hospitals. A failure to gain entry to the research field could seriously compromise the design of the study and site limit to validity and conclusion (Gibbs et al., 2007: 542). However, in many cases researchers need permission to conduct the study, or need to access people who can make important introductions. In this regard, gaining entry requires strong interpersonal skills and involves negotiations with gatekeepers who have the authority to permit or restrict entry to the required community or group (Sussex, Herne & Scourfield, 2008: 403; Polit & Beck, 2008: 70 & 206). In this study, the gatekeepers were controlling officers in the MoH, Lilongwe and Salima District Health Officers, KCH and Nkhoma hospital management and NdiMoyo palliative care management.

After getting written permission from the MoH to conduct the study, the researcher sought permission from the DHOs of the two districts who were the gatekeepers of health-related research in the chosen districts. The researcher briefed the DHOs from the two districts on the nature of the study, after which they gave written consent to the researcher to conduct the study in their respective districts. After that, the researcher secured appointments with the Hospital managers of KCH and Nkhoma hospitals and the manager of NdiMoyo palliative care clinic, each of whom was responsible for the clinics selected for study. The hospital management were also asked for consent, which was granted after they understood what the study would involve. Hospital management introduced the researcher to the palliative care clinic managers who then introduced the researcher to palliative care nurses and explained to them about the study and their role. The palliative care nurses then assisted the researcher in identifying study participants since HIV was still a sensitive topic to introduce to participants. The researcher’s professional background as a nurse assisted her in obtaining access to the hospitals and palliative care centre.
without difficulty. However, the researcher had to maintain a neutral stance to avoid influencing the results of the study during data collection.

### 2.6.2 Establishing rapport and developing a trusting relationships

A field researcher builds rapport by getting along with members in the field. Building rapport and trusting relationships with study participants and people working at the study sites is important for the researcher to be regarded by participants as an “insider” as opposed to a stranger who is interrupting normal activity (Polit & Beck, 2008: 404). The researcher’s image could thus negatively affect the outcome of the study if she is regarded as a stranger. In this study, the researcher worked strategically and relationally to build rapport and trust, and develop a positive image among participants. At the DHO the researcher reported at the hospitals where the Hospital Nursing Manager who then introduced the researcher to other palliative care members. At the NGO clinic, the clinic managers introduced the researcher to other team members.

While preparing to collect data, the researcher established rapport and a trusting relationship with informants and gate-keepers by spending two months in the study areas. During this time the researcher became familiar with the conversation pattern, norms and values of the study settings and gained the confidence of the gatekeepers. A week prior to data collection, the researcher met with the study participants to establish rapport and explain the purposes and benefits of the research study. Establishing rapport with the gatekeepers and seeking permission allowed the researcher easier entry into the study sites; and building rapport with the participants prior to discussions facilitated a more comfortable and safe environment for open and honest dialogue.

### 2.6.3 Interviewing techniques used by the researcher

The researcher facilitated all individual interviews and focus group interviews, and in so doing adopted a non-judgemental and unbiased attitude during the research process in order to encourage participants to share their thoughts and feelings. In addition, the researcher had to employ a range of communication and group facilitation skills in order to carry out activities successfully. These are discussed below:
• **Probing**
Probing was utilized by the researcher during individual and focus group interviews. According to Polit and Beck (2008: 763) probing is described as eliciting more useful or detailed information than was volunteered in the first reply; for example, saying: “That is interesting, please elaborate,” or “anything more?”

• **Bracketing**
Is a technique of holding in abeyance any preconceived beliefs and opinions about the phenomenon under study (Polit & Beck, 2008: 748). In addition, the same authors state that although bracketing cannot be achieved totally, researchers strive to bracket using a reflexive journal. In this study, the researcher used the reflexive journal during data collection and analysis to reflect and self evaluate to achieve effective bracketing.

• **Reflecting**
This was utilized during data collection. During data collection and analysis, the researcher engaged in reflection on personal feelings and beliefs that could influence the phenomenon under study (Polit & Beck, 2008: 764). Data was analyzed as soon as possible to determine the direction of each contact session. Reflecting after each contact session directed the researcher to plan for the next session.

• **Intuition**
According to Polit and Beck (2008: 228), intuition is achieved when researchers remain open to the meanings attributed to the phenomenon by those who experienced it. The researcher achieved this through complete concentration with the phenomenon under study to increase knowledge.

• **Clarification**
Involves confirming what a person has said to ensure a mutual understanding and make it clearer (Sussex et al., 2008: 141). Clarification was utilized during this research. For example, the researcher said: “Let’s see whether I understood you correctly, you said that …”
• **Silence**
In an interview or group discussion setting, silence creates space for thought and processing of information and recovery after a difficult statement. In this study, a brief silence was essential especially after participants respond. Collins English Dictionary (2006: 767) defines silence as “absence of sound”. In this study, silence was used to allow participants to reflect on their thoughts and questions asked during the interviews.

• **Minimal verbal response**
In addition to silence, the researcher used minimal verbal prompts such as “Ee..” (in some African languages “ee” means “yes”) and “Hmm, ..” to encourage the participant to continue with explanation of a point.

• **Non-verbal encouragement**
Collins English Dictionary (2006: 551) defines non-verbal communication as “communication not involving words or speech”. The researcher used non-verbal communication techniques to set the tone for the interviews. For example, the researcher maintained a relaxed facial expression and open posture, and used nodding of the head during the conversation to reassure the participant that she was listening.

• **Summarizing**
According to Collins English Dictionary (2006:831), summarizing involves “a brief account of a process giving the main points of something”. At the end of the interviews the researcher summarized the conversation, and used statements such as “To summarize what you said…..”

2.7 DATA COLLECTION
2.7.1 Pilot study
Although the researcher planned the study carefully, the practical situation was unknown; as such a pilot of data collection tools assisted the researcher to obtain an initial understanding of the practical situation and feasibility of the study (Nunes, et al., 2010: 75). The researcher also utilized the pilot of data collection tools as an opportunity to practice and refine the study design, data collection instruments and analysis plans (Yin, 2011: 37). In addition, the pilot study
assisted the researcher to test the interview guide, modify it and make estimates of the time and cost that was needed (Kimberlin & Winterstein, 2008: 2276). The researcher conducted this pilot of data collection tools with two (2) HIV/AIDS patients, two (2) primary caregivers and one (1) focus group of nurses at Ekwendeni palliative care centre, which is operated under CHAM hospitals in Mzimba district. Ekwendeni palliative care clinic had ten (10) trained palliative care nurses in which three (3) were registered nurses and seven (7) were staff nurses. The researcher used the same semi-structured in-depth interview guide and focus group interview guide that were used in the main study. The pilot was conducted with a sample that would not take part in the main study and in a different district from the main study. After the pilot interview with each group, the researcher and supervisors updated one another regarding the process and research question. The research question for each group of participants was thus refined accordingly to generate appropriate responses. The participants from the pilot group did not form part of the sample and data from the pilot study was not included in the main study.

2.7.2 Data collection strategies
According to Draper and Swift (2011: 3), qualitative enquiry is a large, diverse and evolving field that offers the researcher a wide range of different data collection techniques. The same authors add that choosing appropriate data collection and sampling methods for a qualitative research study can be overwhelming, but is crucial to ensuring high-quality research. Two methods of data collection were utilized in this study based on objectives of the research. Individual interviews, using a semi-structured in-depth interview guide were conducted for both HIV/AIDS patients and primary care givers to collect data. Focus group interviews using semi-structured in-depth focus group guide which had open-ended questions were conducted with palliative care nurses. Reeves, Lewin and Zwarenstein (2006: 291) found that such tools are very strong at generating rich, in-depth data that illuminate our understanding of complex social, behavioral and educational issues. Draper and Swift (2011: 4) assert that interviews are the most widely used technique of data collection in qualitative health research. The researcher, who is trained in conducting focus group discussions and interviews collected data from both samples (Refer to annexure 3 for the in-depth interview guides). Permission to record the interviews was obtained from the participants and explanation on how data would be handled was done in order to establish trust. Interviews were recorded by an audiotape which allowed for transfer of
recorded voice files into the personal computer. The voice files were saved on a password protected file.

2.7.2.1 Semi-structured in-depth interviews
According to Draper and Swift (2011: 4) semi-structured in-depth interviews allow the experiences, meanings, values and priorities of participants to emerge with minimal interference from the researcher. In conducting the semi-structured in-depth interviews of HIV/AIDS patients and primary caregivers, the researcher used open-ended guide questions and where appropriate asked follow-up probing questions to collect the required data (Streubert & Carpenter, 2011: 34). Semi-structured in-depth interviews allowed the researcher to introduce a theme or topic and then let the interviewee develop his or her ideas while the researcher listened (Draper & Swift, 2011: 4).

The researcher took steps to support the value and integrity of the semi-structured interviews. The researcher organized a venue which had no interruptions that would distract interviews. In addition, the researcher, with the consent of interviewees used an audiotape recorder during interviews to ensure that no data was missed. Before the interviews commenced the researcher collected biographical data from participants to provide further context and illumination to the findings. This also ensured that participants recruited met the inclusion criteria.

The researcher constructed three data collection tools for the three groups of study participants. The in-depth interview guide for HIV/AIDS patients was constructed in English and translated to Chichewa (indigenous language for Malawi) for HIV/AIDS patients and the primary caregivers who could not speak English. Data was gathered from six (6) primary caregiver participants from each site, six (6) HIV/AIDS patients’ participants from each site and three (3) groups of nurse participants from the three palliative care sites with four (4), five (5) and six (6) members in each group.

After obtaining consent the participants were met at the clinic in an organised private room for data collection. All individual participants preferred to be interviewed at the clinic on the day of their clinic visit, as opposed to at home. This allowed them to maintain privacy and avoid
suspicion by community or family members. The central question to HIV/AIDS patients was as follows: “Tell me about your palliative care needs in relation to the care that you receive from primary care givers? This question made participants to express their needs. This was a refined question after piloting the data collection tool.

The researcher met some of the primary caregivers when they brought their patients to the clinic, while some primary caregivers were organised by the nurses. All of the sampled primary caregivers preferred to be interviewed at the clinic; depending on the condition of their patient and the amount of time they had available for the interview. The main question for primary caregivers was as follows: Tell me about your needs in relation to caring for your sister/brother/father/mother in palliative care? This was a refined question after piloting the data collection tool. This question enabled participants to answer and express their needs.

2.7.2.2 Planning and conducting individual in-depth interviews

A total of eighteen individual interviews were conducted with HIV/AIDS patients and a total of eighteen individual interviews were conducted with primary caregivers. The researcher conducted six (6) individual in-depth interviews from each site with HIV/AIDS patients and six (6) individual in-depth interviews from each site with primary caregivers. In-depth individual interviews were employed in this study because it gave each participant the opportunity to express their perception and needs of support. Individual interviews are often considered to be the gold standard for researchers to understand how people think about phenomena although the conduction and analyzing of these interviews is time consuming (Yerushalmi, Henderson, Mamudi, Singh & Lin, 2012: 97).

The researcher sought consent and individual appointments a week before the actual date of the interviews from each participant. Permission to use the audiotape was also sought from individual participant to ensure that no discussion is lost by the researcher. The individual interviews were conducted in Chichewa, using the interview guides (See annexure 3 for the Chichewa interview guide). Data collection was conducted until saturation was reached and follow up interviews were conducted immediately with the same participants for 15 minutes after the interviews to validate and confirm data from participants.
Apart from being time consuming, individual interviews have several drawbacks, for example, the interviewer may need to intervene in order to clarify respondents' answers, which could endanger reliability and also as the data collected is extremely rich, there is ambiguity in categorization of the data, endangering validity (Yerushalmi et al., 2012: 97). All the individual participants from the three sites consented for interviews to be audio-taped.

2.7.2.3 Focus Group Discussion

According to Yin (2011: 141) a focus group is a special kind of interview in qualitative research where individuals who have had common experience with a phenomenon are gathered in a group of two to ten participants to discuss specific issues with a moderator who directs the discussion. Richards and Morse (2007: 115) assert that a group should normally consist of six to ten participants, and that the group facilitator or moderator is responsible for the quality of data and balance of the group conversations. This study ensured that each group had four to six participants so that conversations are balanced and the group discussions are well controlled. Streubert and Carpenter (2011: 37) state that focus group interviews are aimed at promoting self-disclosure among participants and capitalizing on group dynamics. In addition, Leung & Savithiri (2009: 218); Draper and Swift (2011: 4) mentioned that focus group interviews ensures access to people’s own vocabulary and concerns, group norms and knowledge since participants build on each other’s ideas. The researcher conducted a total number of three focus groups with a total of fifteen palliative care nurses from the three study sites. There were four (4) participants in the first focus group discussion conducted at Ndimoyo palliative care site; five (5) participants in the second focus group discussion conducted at Nkhoma palliative care site and six (6) participants in the focus group discussion conducted at KCH palliative care clinic. Each focus group discussion took one to two hours and the researcher moderated the interviews.

The focus group interview guide was constructed in English for nurses since English is a medium of communication for them. The focus group discussion guide assisted the researcher to cover all important aspects of the discussion with each group. In the focus group discussion, the researcher used open-ended guide questions and utilized probing to collect the required data. The clinic managers provided a venue with no interruptions to conduct the focus group interviews.
An audiotape recorder was utilized during interviews with the participants’ consent to ensure a full account of the discussion. Before the focus group discussion commenced, biographical data was collected from participants. Spot checking of the data collected was done immediately after the interviews to validate and verify data collected which ensured credibility of the study. Data collection and analysis were done concurrently and data saturation was reached after the third focus group discussion. All the interviews were transcribed verbatim. Proponents of interviews involving more than one participant argue that the verbal interaction within groups reveals a layer of meaning over and above what is gained in individual interviews and that they take into account the fact that individuals do not make decisions or form their opinions in a social vacuum (Draper & Swift, 2011: 4). The main question for the focus group discussion was as follows: ‘Tell me about your needs in relation to supporting primary caregivers of HIV/AIDS patients?’

2.7.2.4 Planning and conducting of the focus group discussions
Planning was done through the palliative care clinic managers responsible for the specific sites where nurses were recruited to be in the focus group discussion. During data collection, the researcher utilized the first ten (10) minutes of the discussion to building rapport with the participants. During this time the researcher collected participants’ background information to assist during the data analysis. This time was also utilized for welcoming the participants’; obtaining consent from individuals and the group; introducing and giving an overview of the topic; setting ground rules and reminding participants about the duration of the session. In addition, the researcher sought to maintain confidentiality by assigning each participant an identity code number instead of using names; in doing this, the researcher aimed to encourage open sharing. The interviews were conducted at the palliative care centres of the specific clinics at the three sites in the two districts for the convenience of the participants.

The researcher facilitated the group discussions and monitored the audiotape recorder. The participants were made comfortable in a semi-circle sitting arrangement to have a full view of each other and for easy facilitation. The researcher sought and received consent to use an audiotape and explained the purpose, simultaneously assuring participants that confidentiality would be maintained. Before commencing the discussion, the researcher clarified that there were
no right or wrong answers, and that differing view-points among participants were expected and encouraged. The audiotape was strategically placed to capture the process of the discussion.

The researcher presented the question and encouraged interaction and discussion between participants (see annexure 3 for focus group interview guide). The researcher probed for more information and clarifications of unclear statements. The researcher encouraged positive and negative comments while remaining neutral and conscious not to make judgements and controlled body language that might communicate approval or disapproval. Data was gathered from a sample of male and female nurses until data saturation was achieved. According to Gibbs et al. (2007: 543) a claim to data saturation is only appropriate when it can be demonstrated that researchers have gained a full understanding of the variety of experiences relevant to their research problem. The audiotape was replayed every time after completion of the interviews as spot checks to confirm the data.

2.8 DATA ANALYSIS

Data analysis is the process of examining the information collected and transforming it into a coherent account in order to reach study conclusions (Green, Willis, Hughes, Small, Welch, Gibbs & Daly, 2007: 545). Data analysis in this study was carried out concurrently with data collection in this study and data saturation was reached when no new information emerged. This process of data analysis involves making sense out of text and preparing data for analysis and moving deeper and deeper into understanding the data (Creswell 2009: 183). Qualitative data analysis requires investment of time and energy and should begin in the early stage of data collection (Ziebland & McPherson, 2006: 40). Data was analyzed using Tesch’s (Creswell, 2009: 185-189) steps and Nvivo version 10 software package. The main aim of analysis of data in this study was to understand the issues of nurses’ support for primary care givers of HIV/AIDS patients in palliative care in Malawi. In achieving this aim, analysis of the needs of HIV/AIDS patients and primary caregivers was first done. The interviews were transcribed and transcripts notes were identified with proper identification code and grouped according to the category of the participants, for example interviews for primary caregivers were grouped together and sites were indicated.
2.8.1 Transcribing of the interviews

Data was collected in different languages and had to be transcribed before using Tesch’s steps of data analysis. Transcription and the art of translation are crucial in qualitative research to ensure valid results and transcribing talk into a written form is an integral part of qualitative research practice (Nikander, 2008: 225). The interviews with primary caregivers and HIV/AIDS patients were conducted in Chichewa. These were also tape recorded and translated into English during transcription. A line-by-line transcription/translation method was used in this study, and a nurse educator who is fluent in both languages conducted back translation. The interviews from palliative care nurses were transcribed verbatim because they were conducted in English, the language that the researcher and nurses speak fluently. In addition, participants had the opportunity to review and elaborate on the transcripts to ensure that their views were accurately represented. Once all data was translated and transcribed Tesch’s steps were utilised.

2.8.2 Tesch’s steps of data analysis

After transcribing the data, Tesch’s (Creswell, 2009: 185-189) steps were utilized in manual data analysis as follows:

Firstly, the researcher read through all the transcripts to make sense of the data and start putting ideas of themes. This was followed by picking the most interesting and short transcript, reading through again and underlined meanings and wrote down the thought. The researcher then made a list of all topics and grouped familiar topics together, and listed major topics, unique topics and left over topics. Secondly, the researcher took the list of topics and went back to data where all topics were abbreviated as codes and codes were written next to the appropriate segments to see if new categories and codes emerged. Thirdly, the researcher found the most descriptive wording for the topics, and then turned them into categories and then reduced the total list of categories by grouping topics that were related to each other. Finally, a final decision was made on abbreviations for each category and codes were alphabetized and data belonging to each category was assembled in one place where all the existing data was recorded.

The external coder was provided with the guide that the researcher used to analyze the gathered data and was supplied with the objectives of the study and the protocol for coding and decisions
on emerging theoretical explanations. Thereafter the researcher and an external coder reached a consensus on categories and subcategories identified in the data. Emerging themes were evaluated after each transcription was completed, within three weeks from the date of the interview. This process was followed by the use of Nvivo version 10 software package for data management.

2.8.3 Data Analysis using Nvivo software package
After data analysis using Tesch’s steps, data was exported into Nvivo software package version 10 in three groups according to participants’ categories. Nvivo software package was used in data analysis for credibility of the study and does not do the thinking for the researcher. The researcher managed data from each group of participants by assigning codes to segments of text and similar codes were grouped. Two types of codes were formed; super codes that described the main themes and ordinary codes that specifically described the details of each super code which are the categories of the themes. However, some segments of data were coded under two or more codes because such segments fitted on different codes. Lastly, the themes that emerged were discussed with the external coder and consensus was reached. When all the data collection and analysis was completed, the researcher read through all the transcripts again several times to ensure that participants’ world has been correctly represented.

2.9 REASONING STRATEGIES OF THE RESEARCHER
The researcher utilised different reasoning strategies to facilitate the research process and to formulate logical arguments about HIV/AIDS patients, primary caregivers and Palliative Care Nurses. According to Burns and Grove (2007: 16) reasoning is described as the “processing and organizing of ideas in order to reach conclusions.” Adding to this, Polit and Beck (2008: 13) view logical reasoning as a problem-solving method that combines experience, intellectual faculties and formal system of thought. The same authors view deductive and inductive reasoning as a useful means of understanding and organizing the phenomena (Polit & Beck, 2008: 13). Streubert and Carpenter (2011: 10); Chinn and Kramer (2008: 214) outline inductive and deductive reasoning in theory building. However, Walker and Avant (2011: 65) outline analysis, synthesis and derivation as the three basic reasoning strategies used in research. In this
research study the researcher used four reasoning strategies to reach to a logical conclusion namely: analysis, synthesis, induction and deduction. These strategies are described as follows:

2.9.1 Analysis
In analysis, the researcher clarifies, refines and sharpens concepts or statements. Analysis according to Walker and Avant (2011:64) is described as an approach by which the theorist dissects a whole into parts, allowing one to clarify, refine or sharpen concepts, statements or theories especially where there is existing body of knowledge for better understanding. The same authors explained that analysis allows the theorist to examine and re-examine existing knowledge about the phenomena to improve the accuracy, currency or relevance of the knowledge (Walker & Avant 2011:64). Analysis leads to identifying, refining, classifying and sharpening of concepts.

The researcher applied analysis reasoning to dissect the data into parts so that it can be understood during data analysis. This assisted in identifying and classifying the categories and relationship of concepts that emerged to other categories in palliative care for HIV/AIDS patients, primary caregivers and palliative care nurses which could also form statements.

2.9.2 Synthesis
Synthesis is the process of building up separate elements into a connected whole. In synthesis reasoning a theorist combines isolated pieces of information that are theoretically unconnected which aids in sifting out important factors in large amount of data (Walker & Avant, 2011:63). In addition, Walker and Avant (2011:63) state that synthesis works well where the theorist is collecting or interpreting data without an explicit theoretical framework.

In this study the strategy was applied to identify relationship between concepts and categories and construct new concepts, categories and statements. In addition, synthesis was utilised when drawing conclusions and making recommendations based on findings from the individual semi-structured in-depth interviews and focus group interviews after distilling out important factors.
2.9.3 Inductive reasoning

Inductive reasoning is described by Streubert and Carpenter (2011:10) and Delport and De Vos in De Vos, Strydom, Fouche, and Delport (2011: 49) as a process of reasoning that starts with details of experience from specific observations which moves to a more general theoretical explanation of the phenomenon. In inductive reasoning, particular instances are observed to be consistently part of the larger whole or set which is merged with the larger whole (Chinn & Kramer, 2008: 214). The same authors state that with induction people induce relationships by observing or experiencing an empiric reality and reaching conclusions.

In this study, inductive reasoning strategy was utilized when exploring the needs of primary caregivers, palliative care nurses and HIV/AIDS patients during data collection. The concepts that emerged were refined by the researcher to then generate empirical generalizations. This form of reasoning was important during development, description and evaluation of guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care.

2.9.4 Deductive reasoning

According to Chinn and Kramer (2008: 214), deductive reasoning is described as a logic in reasoning from the general to the particular using two or more variables. Streubert and Carpenter (2011:10) describe deductive reasoning as a strategy that moves from the general to the specific. In addition Delport and De Vos in De Vos, Strydom, Fouche, and Delport, (2011: 48) state that deductive reasoning is a form of reasoning where two premises are relevant and moves from the general to the specific.

In this research study, deductive reasoning was used during the following instances: during discussion of key findings and their relationship to literature, after analysis of data from focus group discussions and semi-structured in-depth interviews and when drawing conclusions and making recommendations on the needs of palliative care nurses, needs of HIV/AIDS patients and needs of primary caregivers. It was also used in generation of statements for the guidelines, describing of the guidelines and identification of concepts based on the findings of the research.
2.10 TRUSTWORTHINESS
According to Curtin and Fossey (2007: 88), trustworthiness is the extent to which the findings are an authentic reflection of the personal or lived experiences of the phenomenon under investigation. Streubert, Speziale & Carpenter (2007: 98) reported that trustworthiness of data is established when participants recognise the findings of the study to be true. Establishing trustworthiness of research increases the readers’ confidence that the findings are worthy of attention (Law, 2002 cited in Curtin & Fossey, 2007: 89). The researcher made use of Lincoln and Guba’s Framework (1981; 1985 and 1994 in Streubert and Carpenter, 2011:47 – 51; Richards and Morse, 2007:189 – 202; Polit and Beck, 2008:539 - 540) to ensure valid results and trustworthiness of the study. Lincoln and Guba’s framework is based on five criterions namely:

- credibility
- dependability
- confirmability
- transferability and
- authenticity.

2.10.1 Credibility
Credibility deals with establishing confidence in the findings and how the findings match with reality (Sinkovics, Penz & Ghauri, 2008: 690. This is achieved by testing the findings with the participants where data was taken or who are familiar with the phenomenon under study.

To ensure credibility the researcher used triangulation of data collection methods and collected data from multiple sources. The researcher utilised individual semi-structured in-depth interviews with primary caregivers and HIV/AIDS patients and also used focus group discussion for palliative care nurses as data collection tools. The researcher provided thick descriptions of strategies used in the study, and provided evidence by direct quotations from participants. The other strategies used were utilizing the services of an independent coder and use of peer debriefing with supervisors who are experts in the field of qualitative research (Curtin & Fossey, 2007: 88).
During analysis, an independent coder who is experienced in qualitative research and the researcher held discussions together regarding analysis in order to reach a consensus and conclusion. The research supervisors were also involved in the planning until the final stage of report writing to ensure credibility. Another strategy that was used is member checking. Member checking ensures that the participants recognise the findings as true to their experiences and are accurate (Streubert & Carpenter, 2011: 48; Curtin & Fossey, 2007: 92). In addition, the researcher’s experience enabled efficient conduction of this research. This method was also utilized in this study to ensure credibility.

Furthermore, prolonged engagement was also used in this research. Prolonged engagement refers to the investment of sufficient time collecting data to have an in-depth understanding and ensure saturation of the information (Polit & Beck, 2008: 542). During the individual semi-structured in-depth interviews the researcher spent 45 minutes with the participants. The researcher spent one to two hours with participants in the focus group discussion. In addition, the researcher spent three months immersing in the data during data analysis to have an in-depth understanding and identify recurring themes which ensured achievement of prolonged engagement.

2.10.2 Dependability

Dependability is a criterion that ensures that data is stable and reliable over conditions and time (Polit & Beck, 2008: 539). This strategy ensured that the findings be similar if the study is repeated with the same subjects or in a similar context. To achieve this, the researcher used an audit trail where details of how data was collected, how categories and decisions were made, and experts validated and evaluated the guidelines. An audit trail is a detailed, comprehensive accounting of all data collection; data analysis activities and accurate, comprehensive records of the methods employed in the research to serve as reference for the reader (White, Oelke & Friesen, 2012: 251-252). Data was analysed by the researcher and an external coder to ensure dependability. In addition triangulation was used to ensure dependability. Triangulation is used to better capture a holistic view of the phenomenon being studied and offers depth and breadth leading to a greater understanding of the phenomenon as each research strategy used contributes a different piece to the puzzle ensuring completeness of the results (Curtin & Fossey, 2007:90). This study used triangulation method and multiple sources to enhance dependability and
credibility. Data was collected using individual in-depth interviews and focus group interviews and the multiple sources included primary caregivers, PLWHA and palliative care nurses which ensured dependability.

Furthermore the researcher used reflexivity, which is to continuously reflect on beliefs and assumptions to ensure that might alter results to ensure that dependability is achieved. Researcher reflexivity is considered an integral aspect of ensuring ethical conduct acknowledging the importance of developing positive relationships between researcher and participants (Wilson, 2011: 2068). Reflexivity involves the direct acknowledgement by the researcher that he or she is an active participant throughout the research process and therefore could influence the development of the research and the engagement of the participants (Finlay, 2003 cited in Curtin & Fossey, 2007: 93). The researcher was therefore explicit about personal biases, assumptions and values that could have some influence on the research process and affect findings by reflecting her own beliefs rather than those of the participants.

The researcher also used peer debriefing throughout the research study to achieve dependability. The study was supervised by two qualitative research experts who are advanced practitioners in nursing who discussed about the study and reached consensus of the study process at various stages that ensured achievement of dependability.

2.10.3 Confirmability
According to Polit and Beck (2008: 539) confirmability is concerned with establishing that data represent the information that participants provided and not the researchers’ imaginations. In addition Streubert and Carpenter (2011: 49) state that the objective of confirmability is to illustrate clearly the evidence and thought that led to conclusions. This requires that data is free from researchers’ bias which was achieved by use of bracketing and reflecting on her beliefs on the phenomenon under discussion to avoid influencing the data. An audit trail, pilot study and assistance of independent coder assisted in achieving this, as well. Finally, this was also achieved by making sure that information was audio recorded and transcribed; therefore minimizing potential for researcher bias and allowing for direct, source-based confirmation of data.
2.10.4 Transferability

According to Streubert and Carpenter (2011: 49), transferability refers to the probability that the study findings have meaning to others in similar situations, which they labelled as “fittingness”. This was achieved by using triangulation of study sites to get multiple views of participants. The researcher also provided detailed description of participants that would determine if the findings can be applied to other contexts as stated by (Curtin & Fossey, 2007: 92). It is the purpose of this study that health care workers may transfer the results and apply them in similar situations. The researcher has therefore made available thick description of data to people who might need it in order to permit judgments about contextual similarity.

2.10.5 Authenticity

According to Polit and Beck (2008: 540), authenticity is the extent to which researchers show a range of different realities that merged in a research report to show the participants experiences and lives. This was achieved through the following ways; thick description of findings including participants quotes, prolonged engagement with participants, audio-taping and verbatim transcriptions.

Thick description of the research process and findings is essential for a reader to clearly follow what was done, and involves providing a detailed description of the context and circumstances surrounding the phenomena being studied, so that the meaning and importance of behaviours and events can be fully understood (Curtin & Fossey, 2007: 90). In addition, it requires the researcher to provide a rationale for the chosen method, clarify the research process, fully document the methods of data gathering, provide details of the raw data generated, and finally to specify the analysis process undertaken (Higgs, 2001 cited in Curtin & Fossey, 2007: 90).

2.11 ETHICAL CONSIDERATION

Ethical issues may arise in the interaction with HIV/AIDS patients, their primary caregivers and palliative care nurses as such the researcher needs to conform to the standards of conduct in any given situation (Babbie, 2010: 64). This research study used the ethical principles involving human subjects as stipulated in the World Medical Association’s (WMA) Declaration of Helsinki (2008) as follows:
Permission to conduct the study and informed consent

The research proposal was reviewed and approved by the Medunsa Research Ethics Committee of University of Limpopo in South Africa (Reference number: MREC/H/13/2012: PG) and the National Health Sciences Research Committee (NHRC) of Malawi (Reference number: NHSRC992). Thereafter permission was sought from the DHO of the Salima and Lilongwe districts (see appendix E and F). After obtaining ethical clearance from the DHO of the two districts, permission was sought and obtained from management of the three research sites (Appendix H, I and J). Written informed consent (see appendix L and M) was obtained from each participant before conducting the research study. Participants were informed about use of an audio-tape recorder during the interviews and they gave consent for this to be used. The information sheet and consent forms were given to each participant to be completed by each participant and contact details of the researcher were provided for further clarifications if necessary. The information sheet was translated into Chichewa for participants who could not speak English. This was an ongoing process until data collection was completed from all the participants.

Palliative care nurses were assured that their employment status would not be affected by participating in this study. All nurses who participated gave verbal and written consent and information leaflets were given to them before hand so that they could make an informed choice. This process of obtaining informed consent showed that the study was carried out with full awareness of the participants.

Autonomy

Autonomy has been defined as the capacity to think, decide, and act on the basis of a freely made decision (Townsend, Cox & Li, 2010: 620). The researcher explained to participants that participation in this study is voluntary and participants were allowed to make a free, independent and informed choice without coercion (Holloway & Wheeler, 2010: 54). Participants had the right to withdraw from the study at any time and for any reason which is a voluntary dimension of autonomy in qualitative research (Houghton, Casey, Shaw & Murphy, 2010: 16). One of the pre-requisites for obtaining consent is being provided with information so that an informed
decision can be made (Wilson, 2011: 2071). The researcher obtained informed consent from all participants in the participants’ local language for those who could not speak English and information about the study was given in the participants’ local language and clarifications were made so that participants make an informed decision before taking part in the research. (See annexure III D for participant’s information leaflet). The researcher explained to participants on how data would be handled during the study and after (WMA Declaration of Helsinki: 2008: 2 - 3).

**Protection from harm**

The researcher made sure that the well-being of the individual research participants took precedence over all other interests (WMA Declaration of Helsinki, 2008: 1). The researcher explained that there are no expected physical and social harm in this study, however if participants experienced emotional discomfort from being researched, the interview was going to be terminated and the participant was going to be counselled and supported as necessary (Houghton et al., 2010: 19). The researcher arranged with a colleague who was a psychologist to assist when the need arises. However, none of the participants experiences distress nor did need counselling.

The researcher took steps to minimise the potential for unintentional HIV status disclosure for the participants. Firstly, the palliative care nurses assisted the researcher in selecting HIV/AIDS patients according to inclusion criteria. Secondly, the researcher met each potential participant separately in an organised private room at the clinic after they had accessed palliative care services.

**Confidentiality**

Maintaining confidentiality can be challenging in qualitative research due to the detailed descriptions used to illustrate and report the findings, but should be addressed in relation to individual participants and sites in which the research is conducted (Houghton et al., 2010: 20). Confidentiality of participants was maintained throughout the study by not attaching names to the collected data but using identification codes. Name descriptions that could easily be identified in the report were omitted to ensure confidentiality. Information shared by participants
was kept confidential and only those directly involved in the study, such as the external coder and research supervisors had access to raw data, and participants were also informed about this. All written transcripts were kept under lock and key in a safe place only accessible to the researcher and the voice notes were kept in a separate private computer drive and only accessible to the researcher using a password. The hard copies of transcripts were also kept in a separate cabinet from the signed consent forms so that information could not be easily linked.

Also, participant’s names were omitted in the results to ensure confidentiality. The researcher transcribed the interviews herself and a confidentiality agreement was signed with the independent coder. Duplicates for the audio would be kept in a safe and private location as a backup for a period of five years. The researcher did not disclose any information for participants to any other participant who took part in the research study. As required by WMA Declaration of Helsinki (2008: 3) the researcher took every precaution to protect the privacy of research subjects and maintain the confidentiality of their personal information. Finally, the researcher conducted the interviews in a private room with no interruptions.

**2.12 THE INTEGRATIVE LITERATURE REVIEW**

An integrative literature review was conducted after data analysis as part of the research process to assist in developing of the guidelines. This process assisted in synthesizing existing evidence regarding support of primary care caregivers which was the aim of the study. The integrative literature review followed the Whittemore and Knafl’s (2005) process as a guide. According to Anthony and Jack (2009: 1172) an integrative literature review using Whittemore and Knafl method guides the summary and analysis of literature for the purpose of drawing conclusions that provide a more comprehensive understanding of a particular phenomenon since it uses eligible primary sources and incorporates explicit and systematic processes which increases analytic rigour. Whittemore and Knafl (2005: 546) distinguish the integrative method from other review methods as the only approach that allows a combination of diverse methodologies as well as empirical and theoretical sources increasing the role in clinical practice and evidence-based practice initiatives. Robinson, Gott and Ingleton (2014: 20) added that data relevant to the particular topic is then analyzed and themes are identified, grouped, compared and then presented.
Whittemore and Knafl (2005: 549) process in an integrative review have to identify the problem to be researched, search the literature and evaluate data but also analyze the data and present it to achieve tangible results. Morrison and Symes (2011: 164) adds that in an integrative review, literature searching strategies are utilized in different databases for studies meeting a specified criterion using a combination of key words in order to address a research question. This integrative review utilized the following research question to guide the process: What evidence exist in literature regarding support to primary caregivers of HIV/AIDS patients in palliative care?

The support phenomenon is relevant to most disciplines and the understanding of this concept is vital in nursing practice including palliative care. Different literature studies have looked at providing palliative care to HIV/AIDS patients. However, the researcher’s clinical and academic experience led to the awareness that the support phenomenon for caregivers is not well explained in nursing literature and palliative care. Nurses who work with caregivers of HIV/AIDS patients require theoretical and practical understanding of the support process.

2.13 GUIDELINES DEVELOPMENT PROCESS

The guidelines development in this study followed the process laid down by Evidence-Based Guidelines Development (EBGD) and the National Institute for Health and Clinical Excellence (NICE) which was modified to suit the study. This process ensured that the draft of the guidelines were developed by the researcher and then refined by the experts.

2.13.1 Evidence-Based Guidelines Development and National Institute for Health and Clinical Excellence methods

The EBGD and NICE methods were adapted and followed in the development and refining of the guidelines using four steps. Evidence-Based practice guidelines and NICE guidelines are defined as systematically developed statements to assist the practitioner and patient to make decisions about appropriate health care for specific clinical circumstances, although they are also relevant to health service managers (The Evidence-Based Care Group, 2006; NICE, 2006). The NICE and EBGD methods are underpinned by the key principle of basing recommendations on
the best available evidence; and involving stakeholders but also Appraisal of Guidelines for Research and Evaluation (AGREE) using the six domains to ensure quality of the guidelines which are as follows: scope and purpose, stakeholder involvement, rigour, clarity and presentation, applicability and editorial independence (Qaseem, Snow, Owens & Shekelle, 2010:153).

2.13.2 Application of the modified EBGD and NICE process in this study
The EBGD and NICE process were modified in this study for different reasons. The EBGD process develops guidelines after being requested by the hospital organizations upon the need. In this study, the need was identified by the researcher with guidance from the two supervisors. According to the EBGD process, stakeholders who are experts in the field are involved from the initial selection phase up to the review and revision phase. In the selection phase a team leader and members are selected and evidence from research is reviewed together with them, clinical question is formulated, current goals are explored and key aspects to be included are identified. However this study utilized the researcher in this process and the guidance of supervisors in fulfilment of the PhD requirements. This researcher involved stakeholders/experts in the guidelines development phase where they were oriented to the process, the role of evidence and provided with the draft of guidelines for input. This study also utilized the external review phase where it involved different experts for input on the guideline. After guidelines were formulated, appraisal was performed using AGREE tool which is one of the processes followed in the EBGD process. These selected phases were adopted and combined with some of the NICE steps according to the scope of this study through guidance of the two supervisors.

This study also utilized some of the NICE stages. The scope of the guidelines was explored with guidance from the supervisors and this information was shared with experts. In stage three of the NICE process guideline development group is formed, this process was conducted by the researcher where experts were selected for input on the guidelines with guidance from supervisors. NICE process involves formulation of the clinical questions which guided the guidelines development process in this study. NICE process also involves writing a consultation draft of guidelines which is given to experts for comments which was followed in this study. The process also requires that in the first round, comments on the drafted guidelines be reviewed and
preparation of the final draft which is also given to experts for comments before preparing the final guideline. This process was also utilized in this study. The selected EBGD process and NICE process were then modified and adapted to suit this study. The use of EBGD and NICE process was referenced accordingly and NICE indicates that their guide could be used for educational purposes and cited accordingly which was followed in this study (NICE, 2006).

2.13.3 Selection of experts
The researcher selected thirteen experts who contributed to reviewing and refining the guidelines. This was a purposive sample selected based on the experts’ work experience, and knowledge of the subject matter. According to Fretheim, Schunemann and Oxman, 2006: 15; Baker, Lovell and Harris, 2006: 60) selected experts need to have different perspectives, trends of thought, information, approaches and practical experiences. Before consulting the experts, the researcher had a list of prospective experts and obtained their contacts through colleagues and Ministry of Health. These experts included nursing professionals, clinical officers, nurse educators, policy makers, managers, patients and caregivers who represented stakeholders. The NICE and EBGD process does not require experts to be blinded, however some experts in this study requested that their names be blinded and their positions revealed which was followed.

2.13.4 Refinement of the guidelines
The EBGD and NICE process was followed in refining the guidelines. The researcher developed the draft of guidelines based on research results and an integrative literature review, which was shared with experts. Due to geographical distribution of the selected experts, initial communication was conducted by telephone with some, e-mail with others and face-to-face meetings with the remaining experts. After the initial contact, the researcher sent the drafted guidelines to some experts electronically while others preferred a hard copy. Three rounds were used to achieve consensus on the guidelines. Chapter six discusses the guidelines in detail.

2.14 SUMMARY
This chapter discussed the appropriateness of a qualitative, descriptive and explorative approach utilized in this study. It also described the context and setting of the study, the purpose of the research, population and sampling. Furthermore, it described in detail the ethical considerations,
data collection, data analysis and strategies to ensure trustworthiness of the study. It has also discussed briefly the integrative review and guidelines development process. The next chapter discusses the results of this research study.
3.1 INTRODUCTION
This chapter discusses the findings of this study, as drawn from data collected through qualitative research methods from palliative care nurses, HIV/AIDS patients and their primary caregivers from the three palliative care sites in Malawi. The sites are named as follows: Ndimoyo palliative care centre (non-governmental organization (NGO) representing group 1, Kamuzu Central Hospital (KCH) (government) palliative care clinic representing group 2 and Nkhoma hospital (private) palliative care clinic representing group 3 of the participants. The aim of the study was to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. From needs of the three groups, guidelines were developed to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. In this chapter, the first section discusses findings from palliative care nurses; the second section discusses findings from primary caregivers and the last section of the chapter discusses findings from HIV/AIDS patients. Each section will start with a discussion of participants’ baseline characteristics.

SECTION 1: ANALYSIS OF FINDINGS FROM PALLIATIVE CARE NURSES
This section discusses findings from palliative care nurses from the three sites where three focus groups were conducted, one from each site. The first part of the section has discussed baseline characteristics of the participants and the second part has discussed the main findings of the study.

3.2. BASELINE CHARACTERISTICS OF PALLIATIVE CARE NURSES
A total of fifteen (15) palliative care nurses were purposively selected from a population of 244 as information rich participants from the three study sites. Of these, fourteen were females and one (1) was male. These participants were in three groups according to the study sites as follows: group one (1) had four (4) participants and was from Ndimoyo palliative care centre; group two (2) had six (6) participants and was from KCH Palliative Care Clinic and group three (3) had five (5) participants and was from Nkhoma hospital palliative care clinic. Baseline characteristics of participants consisted of six areas namely: age, gender, nursing cadre, palliative care training, employment condition and period worked in palliative care.
The results indicated that 10 participants’ ages ranged from 41 to 50, four of them ranged between 31 and 40 years and one of them ranged between 51 and 60 years respectively. This could show that most nurses working in palliative care have age ranges between 31 and 50 years in Malawi.

Participants also stated their cadre which showed their level of nursing training. Eight participants were enrolled nurses showing that they had a certificate in nursing and seven participants were registered nurses showing that they either had a diploma or degree in nursing. Out of the 15 participants five had palliative care training in Uganda and 10 had palliative care training in Malawi. Dgedge, Mendoza, Necochea, Bossemeyer, Rajabo and Fullerton (2014) stated that availability of more qualified nurses improves the quality of nursing care and better outcomes of patients.

Participants were asked their employment condition and six were working full time in palliative care clinics while nine were working on part-time basis. In addition, 14 of them had worked for more than a year in palliative care clinic and one participant had worked for less than a year in the clinic. This could indicate that most nurses had experience in palliative care provision.

3.3 THEMES, CATEGORIES AND SUBCATEGORIES FROM PALLIATIVE CARE NURSES

Data collected from palliative care nurses was organized into themes which are the central and recurring ideas found in the text. One main theme which emerged from the data was needs of palliative care nurses. From this theme, categories which were the content with similar information were grouped. Five categories emerged which pertained to training of palliative care nurses, need for resources, need for support of palliative care nurses, need to support primary caregivers and guidelines used by palliative care nurses. From these categories several subcategories emerged which are the subdivisions that have common differentiating characteristics within the categories and are discussed and summarised in Table 3.2 below.
<table>
<thead>
<tr>
<th>Main theme</th>
<th>Categories</th>
<th>Sub-category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs of palliative care nurses</td>
<td>1. Need for training of palliative care nurse</td>
<td>• Duration and quality of the training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Content of palliative care training</td>
</tr>
<tr>
<td></td>
<td>2. Need for resources of palliative care nurses</td>
<td>• Need for adequate space</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Need to increase human resources</td>
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<tr>
<td></td>
<td></td>
<td>• Need for clinical supplies</td>
</tr>
<tr>
<td></td>
<td>3. Need for palliative care nurses support</td>
<td>• Need for support from fellow nurses</td>
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<td>• The need for palliative care monitoring by the DHO</td>
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<td>4. Need for support of palliative care nurses</td>
<td>• Limitations of palliative care nurses in supporting</td>
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3.3.1 Category 1: Need for training of palliative care nurses

Two subcategories emerged from this category that related to the duration and content of training which affected the knowledge of palliative care nurses. These subcategories are discussed as follows:

### 3.3.1.1 Subcategory 1: Duration and quality of palliative care training

Participants felt that the duration and quality of palliative care training in Malawi was inadequate to provide them with the necessary skills to care for HIV/AIDS patients and support primary caregivers. Five nurses comprising of three registered nurses and two enrolled nurses who trained in Uganda indicated that they were better equipped due to the longer training duration of eight weeks than the one to two weeks training provided in Malawi which the other ten nurses attended. This was explained in the following quotations:

“All my colleagues and I were trained in Uganda...we trained in Uganda because we were not impressed with the course that they provide here...we were sent to Uganda for a one week theory and two weeks practical placement then we went back for an initiators course which was for five weeks.” (Group 1, Ndimoyo Palliative Care Centre).
“I did the one week theoretical training here in Malawi and it is only now that I am learning from my colleagues as I work here, so one week training is not enough to make one a provider...”. Group 2, KCH Palliative Care Clinic.

Some of the participants suggested that palliative care knowledge could improve in Malawi if the course is included during initial basic nursing training. They felt that this could assist in improving knowledge and sharing the importance of palliative care than the in-service training provided through workshops. This was expressed by participants as follows:

“The other thing is to start palliative care at grassroots...which is during nursing training...this would assist all nurses to have knowledge from their training...so this component needs to be included in the curriculum”. (Group 3, Nkhoma hospital palliative care clinic).

“I think that if palliative care can be taught in nursing schools, knowledge and the value of palliative care would improve and it would be looked at as important. I learnt palliative care during my general nursing training in United Kingdom and it should be like that...what would really help is the practical part so that it makes sense and then you could decide to work in palliative care or not. (Group 1, Ndimoyo Palliative Care Centre).

3.3.1.2 Subcategory 2: Content of the training
In addition to the quality and duration of the training, participants suggested that the current palliative care training is too narrow, and does not cover all the relevant aspects of palliative care which needs that the content be broaden to make it comprehensive. Participants felt that components such as pain management and counselling of patients with both HIV and cancer needed to be included in the training. This was expressed as follows:

“The government should send palliative care providers for training on how to counsel and assist patients with both HIV and cancer...”. (Group 2, KCH Palliative Care Clinic).

“I see a challenge with the way we are assessing pain, we are doing it differently amongst ourselves which affects management. The scale that we use is a five finger score but with the
Furthermore, most participants stated that practical training in this area is vital for improvement of knowledge in palliative care. However, some of the participants stated that the training that they attended in Malawi did not include practical training while for others this component was included. This was stated by participants as follows:

“...Here in Malawi they provide one week training and no practical component so nurses lack knowledge and this is affecting palliative care provision in Malawi”. (Group 1, Ndimoyo Palliative Care Centre).

“This training that we had did not include a practical component but only theory, I understand that the training that our friends did included both which makes them to be well equipped”. (Group 3, Nkhoma Hospital Palliative Care Clinic).

3.3.2 Category 2: The need for resources of palliative care nurses

Three subcategories emerged from this category which pertained to a lack of resources in the form of space, human and clinical resources. Participants shared that lack of these resources influenced the quality of care given to HIV/AIDS patients and support of primary caregivers. These subcategories have been discussed as follows:

3.3.2.1 Subcategory 1: Need for adequate space

Lack of adequate space within the health care institution affected palliative care delivery negatively according to participants. This was expressed as an important need which affected care of the patients. This need was expressed in the following excerpts:

“If you have a patient and a caregiver with two of us then the room is just too small...we do not have a storeroom for our medication and other equipment that we need”. (Group 3, Nkhoma Palliative care Clinic).
“I wish we had a room in a separate building, a child friendly environment and a waiting area for our patients. Currently all our patients wait outside this room on that small bench and some are too sick to wait for long periods...there is a lot of noise in this area I wish we had a room like a day ward where patients can rest after getting the first dosage of analgesics before going home”. (Group 2, KCH Palliative Care Clinic).

According to some participants, lack of adequate space also affected privacy of patients since the same consultation room was also used for storage of patient files. One participant expressed this need as follows:

“The challenge is privacy because the same room is used as a consultation room and also storage of patients files and most of the times people will be in and out fetching things from this room,...compromises privacy”. (Group 1, Ndimoyo Palliative Care Centre).

Some participants also shared that in their clinic lack of space affects the efficiency of their work since they only have one consultation room and could only see one patient at a time even if two nurses are on duty. Consequently, patients had to wait for longer periods before they could be seen as expressed by one participant in the following statement:

“I think that we need a palliative care clinic which has two consultation rooms because sometimes there is a long queue outside and with two of us we could be dividing patients and help them quicker than what we are doing now”. (Group 2, KCH Palliative Care Clinic).

3.3.2.2 Subcategory 2: The need to increase human resource

In addition to the need for adequate space, participants mentioned that lack of adequate human resources was impacting palliative care delivery since some sites had only one permanent, full-time nurse and the rest were part-time staff. Part-time staff typically had their primary working site in other wards and would provide relief in the palliative care unit. Participants shared that it is tiresome to work in both their wards and the clinic. This need was reported as follows:
“There is only one nurse allocated permanently here. The rest of us have our wards where we work and sometimes our wards are very busy that we fail to come and report for work here... It would actually be better if there would be three nurses every day since this clinic is run by palliative care nurses”. (Group 2, KCH Palliative Care Clinic.

“The nurses that are here work in different wards and only come here if there is no body since normally there is only one nurse allocated permanently in palliative care clinic...”. (Group 3, Nkhoma Palliative Care Clinic).

“I wish that there were several nursing staff members who were permanently working in palliative care clinic so that we do not have to be moving between our wards and the clinic because it makes us tired”. (Group 2, KCH Palliative Care Clinic).

“The other issue is staffing, we are doing a lot amongst the four of us...we need more staff”. (Group 1, Ndimoyo Palliative Care Centre).

Some participants felt that the lack of adequate human resources affected the care of patients especially counselling. This has been expressed as follows:

“...most of the times you are the only nurse in palliative care clinic and it affects the type of counselling because you want to see other patients as well”. (Group 2, KCH Palliative Care Clinic).

3.3.2.3 Subcategory 3: Need for clinical resources
Participants indicated that a lack of clinical resources also negatively impacted palliative care delivery. The most resources was drugs, particularly vincristine and morphine which are important in palliative care. Participants also mentioned that in some settings patients were required to pay for the drugs and some could not afford which affected their care while other sites experienced shortage of the drugs due to late stocking. This need was stated in the following statements:
“...most of the times we have no drugs...we sometimes run out of drugs to help patients in pain like morphine, so this affects us ...we then start giving alternatives like ibuprofen which are not as effective...". Group 3, Nkhoma Palliative Care Clinic).

“...our patients have to pay for medications and because of poverty they cannot afford to pay for even analgesics and it is very hard now to work in palliative care knowing that you do not have resources to assist patients with...lack of medicinal resources affect care given by caregivers at home and us when we visit”. (Group 3, Nkhoma Palliative Care Clinic).

3.3.3 Category 3: Support for palliative care nurses
In this category, palliative care nurses mentioned about the need for support in their role. According to participants, this lack of support impacted their ability to care for HIV/AIDS patients and adequately support primary caregivers. Five subcategories emerged which related to the need for support from peers, experienced colleagues, management, government and the District Health Officers. These subcategories have been discussed as follows:

3.3.3.1 Subcategory 1: Need for support from fellow nurses
Some participants expressed concern about a lack of peer support which negatively affected their work and they wished to have frequent meetings with fellow nurses in order to share experiences and encourage each other. Participants also shared that this support could assist them in relieving stress and sharing knowledge. This was reflected in the following statements:

“May be we just need to have frequent meetings amongst ourselves in order to share experiences and know how to deal with different situations...we need to support each other through debriefing at the end of each day so that stress does not pile up”. (Group 2, KCH Palliative Care Clinic).

“I feel that even us nurses should encourage each other by conducting meetings which we used to have but now we stopped so we need to start again...”. (Group 3, Nkhoma Palliative Care Clinic).
3.3.3.2 Subcategory 2: Need for support from experienced colleagues
In addition to peer support, some participants shared that they also lacked support from experienced colleagues which negatively affected their palliative care delivery. Participants expressed interest in being mentored by experienced colleagues as a means of performing their roles better. This was expressed in the following quotes:

“...May be we need to mentor each other so that we perform the same way..and then we could be more effective”. (Group 3, Nkhoma Palliative Care Clinic).

“...institutions that are doing well than us such as Saint Gabriel, could assist us through meetings so that we share experiences and they could also mentor and encourage us”. (Group 3, Nkhoma Palliative Care Clinic).

3.3.3.3 Subcategory 3: Need for psychological support
According to participants, working in palliative care clinics affected them emotionally and psychologically requiring psychological support in order to support nurses to cope with the stresses of working with and caring for HIV/AIDS patients. Participants shared that this support is needed due to the stressful environment that they work in, difficult patients’ conditions and a lack of resources. This has been expressed in the following excerpts:

“...each time when I leave this room in the afternoon I am not well. I normally have this heavy feeling within me because of the difficult situations and conditions patients have and sometimes it is because I have been putting myself in their shoes and I struggle to cope. Sometimes because I failed to help someone...most of the times we have patients that have been taking antiretroviral therapy and then they will be told that they have cancer and mostly in advanced stages, so this affects them...this also affects us emotionally and we have no one to talk to”. (Group 2, KCH Palliative Care Clinic)

“This environment is stressful to work in and ...seeing these patients leaves me in a different state than what I was, there is need to relieve burn out. This burn out is due to many things like lack of drugs...”. (Group 2, KCH Palliative Care Clinic).
3.3.3.4 Subcategory 4: Support from management

A majority of the participants articulated the need for nursing management support to better assist with staffing issues and to increase the nurses’ morale of working in palliative care. They also felt that more support could be given in the form of incentives to attract more nurses to palliative care. This was expressed in the following quotes:

“…the nursing side of management is not supportive that is why we have problems with staffing and environment which is affecting our care...There is very little recognition to give people the morale to work here”. (Group 2, KCH Palliative Care Clinic).

“I feel that there should be incentives like locum for nurses to be encouraged and come to palliative care even if they are off duty. Locum makes people work harder”. (Group 3, Nkhoma Palliative Care Clinic).

“Management should consider things like career development in form of specializing in palliative care to work as incentives and encourage people to work in this type of clinic which could be considered as professional support”. Group 2, KCH palliative care Clinic.

“When we just started palliative care, people were supported with lunch but it stopped when management changed, if we could be provided with things for tea or meals. We normally work with no lunch or tea break and we are normally only free around three in the afternoon”. (Group 2, KCH Palliative Care Clinic).

Participants also mentioned the need for management to provide them with a referral system for cases that they could not handle. This was mentioned in the following statements:

“Management could help us by providing someone who we could refer cases we cannot handle ... “. (Group 2, KCH Palliative Care Clinic).
“There’s need for a proper referral system for patients from the clinic to the central hospitals...we should be working together...” (Group 3, Nkhoma Palliative care clinic).

3.3.3.5 Subcategory 5: Need for support from the government

The majority of participants expressed the need for government to support them through the Ministry of Health. They suggested that this support could be in the form of resource provisions so that the clinics do not rely so heavily on donations. Participants from non-governmental organisations also expressed the need for support with medication procurement. This was expressed as follows:

“The Ministry of Health needs to help us with resources so that we can become active as before instead of waiting for donations...The Ministry of Health provides enough resources for home based care programme and my wish is that they should provide for us as well since all patients are important”. (Group 3, Nkhoma Palliative Care Clinic).

“... because we are a non-governmental organization we have to buy everything ourselves and the government does not help us with anything. For example we are buying morphine powder from the government and when they run out of theirs we have to supply the one that we bought from them ...and normally we do not charge...because we do not want patients to suffer...”

(Group 1, Ndimoyo Palliative Care Centre).

In addition, participants mentioned the need for government’s commitment to coordinate palliative care delivery in all the centres to ensure the continuity of patient care and services improvement. The following excerpts support this statement:

“In Malawi there is lack of commitment and coordination between palliative care centres for the government and non-governmental organizations and we wish that this could improve...Palliative care has not started in most government hospitals like Salima because of lack of commitment even if they could have resources”. (Group 1, Ndimoyo Palliative Care Centre).
“I feel that coordination between the district hospitals, Ministry of Health and PACAM is lacking which is affecting the way we conduct palliative care...”. (Group 3, Nkhoma Palliative Care Clinic).

“The ministry of health should make it a point that all ART supplying clinics should have palliative care component so that patients don’t struggle with going to different clinics. I think that we are working in isolation. This lack of coordination is affecting continuity of care...but we need the ministry to assist us so that we can work together”. (Group 2, KCH Palliative Care Clinic).

Participants also mentioned the need for the government to provide more support by developing a palliative care policy. Participants felt that the lack of a palliative care policy limited resource provision and support to primary caregivers. Two participants made the following statements:

“...there is no policy in Malawi that could ensure that resources are provided, that is why we have different ways of caring”. (Group 1, Ndimoyo Palliative Care Centre).

“I feel that if the policy will be available it will help palliative care to grow ...but also resource provision in Malawi”. (Group 3, Nkhoma Palliative Care Clinic).

3.3.3.6 Subcategory 6: The need for palliative care monitoring by the District Health Officers (DHO)

Some participants were concerned with a lack of monitoring of palliative care services by the DHO in the districts. They stated that improved monitoring would ensure proper palliative care service delivery, which would also support them in their role. This was mentioned by participants as follows:

“It is the duty of the DHO to see that palliative care is provided in the district hospitals but it seems like they are not even monitoring...I feel that the DHO need to know what is happening because we send reports every quarter to them as such they could be the right people to follow-up on this issue in their districts”. (Group 2, KCH Palliative Care Clinic).
“The DHO should make sure that all their clinics and district hospitals have palliative care component...I feel that they think that it is not important that’s why they don’t even monitor.... (Group 1, NdiMoyo Palliative Care Clinic).

3.3.4 Category 4: Need to support primary caregivers
Participants highlighted the need for added support for primary caregivers. In this category two subcategories emerged which pertained to the limitations of palliative care nurses to adequately support primary caregivers specifically in relation to the following: arranging transportation to conduct home visits with primary caregivers and patients and mobilising other stakeholders to better support primary caregivers. The lack of support in these areas adversely impacted the role and effectiveness of primary caregivers. These subcategories have been discussed below as follows:

3.3.4.1 Subcategory 1: Need for transport to visit the primary caregivers
Nearly all participants stated that it was important to better support primary caregivers, and that home visitations would be an effective method of increasing interaction and support. Some of them indicated that they now have limited interaction with primary caregivers due to transport problems such that they do not visit the caregivers at home anymore. In addition, others noted that they had never visited primary caregivers and had seen them only when they come to the clinic with the patient. This has been supported in the following statements:

“We have limited interaction with primary caregivers because we don’t visit them, we see them when the patient has just enrolled on the programme because we call for them or if they come to collect medications for the patient...The caregivers who come at all times are the ones that their patient is still very sick or weak, they sometimes come instead of the patient to get his medication or they escort the patient to be reviewed, we don’t have transport to do this”. (Group 2, KCH Palliative Care Clinic)
“Sometimes I feel that caregivers do not share their concerns since we do not visit them at home and you know it takes time to build rapport, lack of visitations also affects our care and support we give caregivers”. (Group 2, KCH Palliative Care Clinic)

“We are concerned about the patients, if caregivers come we counsel them...we do not have transport to follow them up”. (Group 3, Nkhoma Palliative Care Clinic).

“We only see our primary care givers once or twice a week and sometimes once a month, we cannot afford to visit them like before due to transport”. (Group 1, Ndimoyo Palliative Care Centre)

3.3.4.2 Subcategory 2: Other stakeholders to support primary caregivers
All the participants mentioned that they alone are unable to support primary caregivers, and that additional support should come from other sources such as family members, community members, neighbours, volunteers, community leaders and church members. The participants mentioned that they have to play a major role in teaching these groups of people on how they could participate in the care of HIV/AIDS patients. This was expressed in the following statements:

“The first support could come from close family members because sometimes they leave the care for one person...The community or neighbours could also be assisting because you cannot leave HIV care for one person. Community volunteers, health surveillance assistants and even community leaders could also support and assist the patient in different forms...Also church members could assist the patient and caregivers, I feel that it is their duty...we cannot manage to provide this care alone, we need them to assist”. (Group 2, KCH Palliative Care Clinic).

“The other thing is empowering community leaders, I feel that this could help in our absence and things could still be done. Things like having gardens, food preparation ... community leaders could encourage these people on this...If we teach them because on our own things cannot progress. The leaders will not carry this job on themselves but could encourage the community members and primary caregiver on things like drug compliance...If a patient is
refusing drugs the caregiver can have someone to report to at a community level and if they see that they have failed then they can refer back to us”. (Group 3, Nkhoma Palliative Care Clinic).

3.3.5. Category five: Guidelines used by palliative care nurses

The fifth category that emerged from the data was guidelines that could be used by palliative care nurses. From this category, three sub-categories emerged which related to nature of the guidelines, lack of access to guidelines and limitations of the guidelines. These were discussed as follows:

3.3.5.1 Subcategory 1: Current guidelines in use

Currently, guidelines from Ministry of Health exist in Malawi which seem not to be used by all nurses due to different reasons and participants discussed that they use different sources as a guide. This was expressed in the following quotation by participants:

“I personally use the model from Uganda, so that is what has been guiding me but all of us at this clinic are trained in Uganda so we know the model. Fortunately all of us are properly trained in palliative care and we have adequate knowledge to support patients and caregivers”. (Group 1, Ndimoyo Palliative Care Centre).

“We are only using the participants training manual...that is what we have”. Group 3, Nkhoma Palliative Care Clinic).

“Of course we have a guide that has been produced by Ministry of Health and palliative care association of Malawi (PACAM) and it is close to the model from Uganda”. (Group 1, Ndimoyo Palliative Care Centre).

3.3.5.2 Subcategory 2: Access to guidelines

Some participants expressed that they were unaware of any palliative care guidelines and others lacked access because they were not given to them; others mentioned that they knew of guidelines but that they did not use them, instead relied on other resources. The following excerpts reflect this:
I actually don’t know where the guidelines are, may be someone borrowed them...we have some books that we can use....”. (Group 1, Ndimoyo Palliative Care Centre).

“...We were not given the guidelines and we do not know about them...” (Group 3, Nkhoma Palliative Care Clinic).

“We were given guidelines for palliative care, but we do not know where they went...”. (Group 2, KCH Palliative Care Clinic).

3.3.5.3 Subcategory 3: Limitations of the guidelines
In instances where guidelines were available, participants cited some limitations in them, which included that they lack information on supporting primary caregivers; are inconsistently used; and are too broad for application in a clinical setting. These limitations have been expressed in the following statements:

“...the guidelines are also too general; I wish that they could deal with specific issues separately... I wish for extra information to compliment these guidelines for proper care of patients. The other thing about the guideline is that it does not guide us on assisting patients who have both HIV and cancer and this makes it hard for us and even if we wanted to support the caregivers, we do not have a proper guide of how we should do it so this should be the starting point...we cannot apply knowledge from the other guidelines because they are too general”. (Group 2, KCH Palliative Care Clinic).

“I must say that we need to try to be consistent especially for the patient and the caregivers as well since there is no guide on this”. (Group 1, Ndimoyo Palliative Care Centre).

“...we have different ways of caring. But maybe there’s need for guidance on supporting primary caregivers especially at hospital clinics”. (Group 3, Nkhoma Palliative Care Clinic).
“We also need proper guidance on how to support the caregivers because we are not doing it the same way; we just deal with situations as they come...the palliative care guidelines are also lacking that information and this affects care of the patients... even the districts do not have it. I mentioned this because when we send very sick patients to the district hospital they would send them back to us because they would say they did not know what to do”. (Group 2, KCH Palliative Care Clinic).

SECTION 2: ANALYSIS OF FINDINGS FROM PRIMARY CAREGIVERS

3.4 BASELINE CHARACTERISTICS OF PRIMARY CAREGIVERS

From a population of 450 primary caregivers, eighteen (18) were purposively selected as information rich participants from the three study sites. Sixteen (16) females and two (2) males were selected showing that the caregiver role was mostly undertaken by women. Group one (1) was from NdiMoyo Palliative Care Centre, Group two (2) was from KCH Palliative Care Clinic and group three (3) was from Nkhoma Palliative Care Clinic. The following participants’ characteristics were collected: age, gender, and marital status, level of education, occupation and religion.

The results from the study indicate that out of 18 participants from the three study sites 16 of them were females and two were males which indicated that the caregiver role was mostly undertaken by women. This finding is congruent to literature where gender inequities have been noted in HIV/AIDS care giving and 90% of caregivers are women and girls (Newman, Fogarty, Makoae & Reavely, 2011; Majumdar & Mazaleni, 2010:7; APCA, 2008:73.

Participants were also asked to state their ages and out of 18 participants from the three study sites 8 were aged between 31 and 40 years. Six participants ranged between 41 to 50 years while two participants ranged between 51 to 60 years. One participants’ age ranged between 26 and 30 years while another one ranged between 18 and 25 years respectively. This shows that the caring role in this study is taken from the age of 18 up to 60 years. The results from the study conducted by Boon, James, Ruiter, Borne, Williams and Reddy (2010:399) found that older people above the age of sixty were the primary caregivers of children and grandchildren infected or affected by HIV and AIDS due to death of their parents.
In addition participants were asked their level of education using the four levels of schooling system in Malawi. Level one comprises of eight years of primary school education from standard one to eight in which upon completion learners receive a Primary School Leaving Certificate. Level two comprises of four years of secondary education from form one to form four after which learners are given a Malawi School Certificate of Education. Tertiary education comprises of university education in which college, technikon and various tertiary institutions where education and training is offered. Upon completion learners receive degrees, diplomas or certificates. Out of 18 participants interviewed from the three sites 10 had attended primary education, three participants had attended secondary education, four had attended tertiary education and one had no formal education. These results show that the majority of participants had some form of education and most of them had primary education which could influence their knowledge and understanding of their role.

Participants were also asked to state their occupation, and out of 18 participants interviewed from the three sites seven of them were doing businesses, five of them did household farming, three of them were teachers and three of them were unemployed. The observation in this study is that the majority of participants were engaged in businesses which reflected their source of income which could assist caregivers in providing resources for the patient and their families.

In addition, participants were asked to state the period that they have been primary caregivers. The 12 participants reported to have been in this role for more than a year, four were in this role for less than a year and two had been in this role for more than six months. This indicated the different experiences caregivers had in the caregiver role.

Lastly, participants were asked to state their marital status. Out of 18 participants six were married which could indicate support from the husband. Six participants were widows, five of them were divorced and one was single.
3.4.1 THEMES, CATEGORIES AND SUBCATEGORIES FROM PRIMARY CAREGIVERS

Individual in-depth interviews were used to collect data from primary caregivers. Data collected was organized into themes which are the central and recurring ideas found in the text. One main theme which emerged from the data was needs of primary caregivers from which three categories emerged which are the grouped information with similar content. These categories pertained to need for training of primary caregivers, need for resources and need for support. From these categories several subcategories emerged which are the subdivisions that have common differentiating characteristics within the categories and are discussed and are summarised in Table 3.2 below.

**TABLE 3.2: THEMES AND SUB-THEMES FOR PRIMARY CAREGIVERS**

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Categories</th>
<th>Sub-categories</th>
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<tr>
<td>Needs of primary caregivers</td>
<td>1. Need for training of primary caregivers</td>
<td>- Need for primary caregivers to be trained in their role</td>
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<td>- Need to be educated about patients health condition</td>
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<td>2. Need for resources</td>
<td>- Need for clinical supplies</td>
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<td>- Need of financial assistance</td>
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<td>3. Need for support</td>
<td>- Need for nurses to involve primary caregivers in the care of the patient</td>
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<td>- Need for nurses contacts</td>
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<td>- Need for visitations from</td>
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### 3.4.1.1 Category 1: Need for training of primary caregivers

Two sub-categories emerged from this category, and these pertain to the need for caregivers to be trained in their role as well as participants limitations in caring for HIV/AIDS patients due to a lack of knowledge about patients’ condition. These sub-categories are discussed below:

#### 3.4.1.1.1 Subcategory 1: The need for primary caregivers to be trained in their role

Almost all participants expressed the need to be trained in their role as primary caregivers in order to have knowledge and skills to properly care for HIV/AIDS patients. Participants mentioned that the training would assist to increase their confidence and capacity to care for HIV/AIDS patients and reduce frustrations that they face. This was articulated as follows:

“I wish that I get trained to know how to care for my mother in a proper way, the counselling that I am given is not enough to instil confidence in me”. (Participant 1, group 2 KCH Palliative Care Clinic).

“If nurses could teach me properly about what I am supposed to do because I sometimes don’t know what I am doing and it is frustrating...”. (Participant 2, group 3 Ndimoyo Palliative Care Centre).
In addition to being trained, participants mentioned that home visitations by nurses would assist in teaching and supervising them in their role which has been expressed as follows:

“I wish that nurses could visit me at home, train me on what to do”. (Participant 3, group 2 KCH Palliative Care Clinic)

“I was not trained and no one has ever visited me at home to see what I am facing. I wish that I could be properly trained and supported in this role. I give care but lack confidence”. (Participant 5, KCH Palliative Care Clinic).

Some participants felt that they are not being trained because nurses assume that they know their role; this negatively affects the care primary caregivers are able to provide to their patients. This was mentioned in the following statements:

“I think the nurses assume that because I am a teacher I know what to do, but these are two different professions”. ( Participant 2, group 3 Nkhoma Palliative Care Clinic)

“Nurses should not assume that we know how to care for patients, so they should teach us...”. (Participant 4, group 2 KCH Palliative Care Clinic).

3.4.1.1.2 Subcategory 2: Education about patients’ health condition
Some participants in this study expressed that they need knowledge of the patients’ condition, complications of HIV and knowledge of ART and that this lack of this knowledge was affecting the care given to the patient and increasing the stress of caregivers in relation to patient outcomes. The quotes below illustrate this point:

“I need them to teach me about kaposis sarcoma and what I should be doing”. (Participant 5, group 1 Ndimoyo Palliative Care Centre).
“I need proper education from nurses about cancer of the oesophagus because I have the knowledge on HIV...I fail to provide care on this”. (Participant 6, group 1 Ndimoyo Palliative Care Centre).

“I need proper education from nurses about HIV, ART and my baby because it is affecting his growth... and whether this child would reach adulthood”. (Participant 3, group 3 Nkhoma Palliative Care Clinic).

3.4.2 Category 2: Need for resources

Two sub-categories emerged from this category, and these relate to the need for clinical supplies and the need for financial support. A lack of these resources negatively impacted the primary caregivers in their role of caring for HIV/AIDS patients. These sub-categories have been discussed as follows:

3.4.2.1 Subcategory 1: Need for clinical supplies

Most participants noted that they need more clinical supplies to assist their patients. Specific items mentioned included gloves for their protection, medications and necessities for wound dressings; most participants said that these items were too expensive. These needs were expressed in the following quotations:

“I need gloves, medication for my mother and cotton wool for the vaginal discharge. Sometimes the nurses say that they do not have resources like cotton wool”. (Participant 1, group 2 KCH Palliative Care Clinic)

“I need gloves and bandages for my husband’s legs, the nurses sometimes say that they do not have them, we should go and buy but it is expensive”. (Participant 1, group 3 Nkhoma Palliative Care Clinic)

“I also need gloves when caring for my sister, bandages for dressing a wound on her leg and cleaning solution. Normally I have to buy all this because at the clinic they say they have run out
of these each time. These things are so expensive”. (Participant 4, group 2 KCH Palliative Care Clinic)

3.4.2.2 Subcategory 2: The need for financial assistance
Almost all participants indicated that they need financial assistance in order to care for their patients properly. The monetary assistance would help them to buy food for their patient and family, pay bills, buy medications and for other needs that regularly emerge. Participants shared that their role is for both the patient and the patient’s dependants, which is a challenge financially. These financial needs were expressed as follows:

“I also have to find funds for transport to the hospital and for school fees of my two children”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

“My needs are money for food and transport”. (Participant 4, group 2 KCH Palliative Care Clinic).

“My need is financial support; the business which I do does not make enough money because I am mostly at home taking care of my mother. …being the oldest child I have to make sure that I look after my mother, look after my two sisters who still go to school and pay their school fees, pay electricity and water bills using the money from the cakes. It is hard...”. (Participant 3, group 2 KCH Palliative Care Clinic).

Some participants needed financial assistance due to the change of roles in the family. In these instances, patients had been breadwinners but were now sick and could not provide for the family anymore. This was expressed by two participants in the following statement:

“It has been hard for me because initially my son used to look after me and assist me but now I have to care for him. The other thing is that I am struggling financially... ”. (Participant 1, group 1 Ndimoyo Palliative Care Centre).
“He used to sell fish and help me financially but now he cannot so I have to look for food for him…” (Participant 5, group 1 Ndimoyo Palliative Care Centre).

Although ART are given for free, some participants expressed the need for other medications to be given for free. They shared that the hospital closest to them required payment for services, and as such they paid for other medications prescribed for their patient, and the free government hospital was said to be too far away. These participants shared that their patients do not have money support themselves and it becomes the primary caregivers’ role to pay for hospital bills and medications. This was expressed as follows:

“It is a challenge for me and the medications that I get for her are expensive since here we pay for everything except ART… I wish that the hospital could not charge for hospital bills and other things that I need so that I only struggle with food resources, these patients cannot pay for themselves”. (Participant 1, group 3 Nkhoma Palliative Care Clinic)

“…I also wish that nurses could give all the other medications for free because it is expensive to buy and Kamuzu Central hospital is far”. (Participant 1, group 3 Nkhoma Palliative Care Clinic).

3.4.3 Category 3: Need for support for primary caregivers

Five sub-categories emerged from this category, and these pertain to the need for:

- Support from nurses in form of involving primary caregivers in the care,
- Nurses contact,
- Relatives support,
- Support from community members
- Support from the government.

Lack of these forms of support negatively affected primary caregivers in their role and the care provided to HIV/AIDS patients. These sub-categories are discussed as follows:
3.4.3.1 Subcategory 1: Need for nurses to involve primary caregivers in the care of patients

Some participants expressed the need for greater support from nurses to be directly involved in the care of their patients from the outset. These participants felt that this type of support would enable them to be involved in the care of their patients while he/she is admitted in the hospital. They indicated that the lack of such involvement limits their knowledge of their role at home when nurses are not there. This need has been expressed in the following excerpts:

“I just wish that nurses should involve us in the care of the patient especially in the hospital. The nurses and doctors want to talk to the patient only without involving me and at home I don’t know what to do... The other thing is that they do not explain the medications for my son very well and I get confused”. (Participant 5, group 3 Nkhoma Palliative Care Clinic)

“I also need them to teach me thoroughly about my role because I sometimes get confused with his medications especially when he gets sick because nurses do not involve me when they give him medications especially when he gets admitted. At one time he was given new medications on discharge and I gave him wrongly and when we went back for review I was told that I gave it wrongly”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

3.4.3.2 Subcategory 2: The need to have contact details of nurses’

Participants indicated that they needed to be in contact with nurses by use of the telephone. They mentioned that regular telephone contacts would ensure that the caregivers are supported with information and are guided on specific issues that they encounter. This need was expressed as follows:

“I also wish that I could have contact phone numbers for the clinic than to go there each time, sometimes I just need to ask about a specific something...I could be contacting them without waiting for an appointment”. (Participant 6, group 3 Nkhoma Palliative Care Clinic)

“I sometimes wish to have contacts at the clinic so that instead of going with my sister I would just call and be told what to do”. (Participant 2, group 2 KCH Palliative Care Clinic).
“I also want to say that I wish that I could have nurses’ phone numbers to call from home if my son gets very sick or I want to ask for information”. (Participant 1, group 1 Ndimoyo Palliative Care Centre).

3.4.3.3 Subcategory 3: The need for visitations from nurses
In addition to the benefits of telephone contacts participants shared that visitations from nurses would assist in knowledge sharing and encouragement of caregivers. This was expressed in the following quotations:

“I wish that nurses could visit me so that ....they could also check on the care that I give and teach me more so that I improve ... ”. (Participant 3, group 1 Ndimoyo Palliative Care Centre).

“I also need visitation from nurses because it encourages me and also for teaching me”. (Participant 2, group 2 KCH Palliative Care Clinic).

“I also heard that nurses used to visit people in the villages but they have never visited me, I also wish that they could visit so that my husband can also learn what I have heard”. (Participant 1, group 3 Nkhoma Palliative Care Clinic).

“I think that nurses should visit me regularly to encourage me because I sometimes get tired of the caring role”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

3.4.3.4 Subcategory 4: Need for other relatives to be involved in the care
Almost all primary caregivers were family relations to the patient. However, participants expressed a desire for other relatives to provide some support to assist with proper care of their patients to be provided to their patients. They mentioned that this support could be in form of visitations, physical help and financial assistance. The following quotations express this:

“If the families and communities could give full support to the caregivers in different ways whether monetary, materials and physical help it would make our role easy”. (Participant 5, group 3 Nkhoma Palliative Care Clinic).
“My husband has brothers and one sister so when he gets very sick they visit him but they normally don’t help us financially”. (Participant 1, group 2 KCH Palliative Care Clinic).

“My husband has two brothers and one sister, they all used to visit us when he was fine. Now that he is sick, they all rarely visit and only his sister visits more often. Sometimes she brings money or food...I wish that our family members could visit us more and bring the resources like food”. (Participant 1, group 3 Nkhoma Palliative Care Clinic).

3.4.3.5 Subcategory 5: The need for respite support of the primary caregivers
Some participants in this study expressed the need for a break in their role so that they are able to do other personal things such as shopping. These participants were not sure of where to get such support and thought that community volunteers could help. This notion was expressed as follows:

“The only thing that I need is relief sometimes so that I can go to the garden or the shops”. (Participant 1, group 1 Ndimoyo Palliative Care Centre).

“Sometimes I get tired and feel that I need help so that I can have a break and may be go shopping, may be a community volunteer can help”. (Participant 4, group 1 Ndimoyo Palliative Care Centre)

3.4.3.6 Subcategory 6: Need for support from community members
Almost all participants expressed the need for community support in the form of visitations and financial and physical help. Some of the participants expressed that they have this form of support while others indicated that they lacked this support from community members due to stigma and fear of contracting HIV. The following quotations express this:

“My community could also assist by visiting and assisting me when there is need... “. (Participant 2, group 1 Ndimoyo Palliative Care Centre).
“At times the community members visit us but they do not want to share anything with us because of my sisters illness... If I do not have food or resources the community members do not help us”. (Participant 4, group 1 Ndimoyo Palliative Care Centre).

3.4.3.7 Subcategory 7: Need for support from the government
Some participants shared that they need support from the government. They expressed that this support could be in the form of financial assistance and loan availability to assist them to have businesses and food provisions. The following quotations express this:

“I also wish that the government could support me in terms of loans to boost my business”. (Participant 4, group 1 Ndimoyo Palliative Care Centre).

“I wish to have access to a loan so that I have a business to assist me financially”. (Participant 4, group 2 KCH Palliative Care Clinic).

“The other thing is that the government should assist me in terms of assisting the children with school fees”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

“I only want to say that the government should also take an active role of assisting me financially so that I meet my needs. They could also assist with food provisions...” (Participant 1, group 3 Nkhoma Palliative Care Clinic).

SECTION 3: ANALYSIS OF FINDINGS FROM PLWHA

3.5 BASELINE CHARACTERISTICS OF HIV/AIDS PATIENTS
Eighteen (18) HIV/AIDS patients were purposively selected from a population of 1154 patients as information rich participants from the three study sites, nine (9) males and nine (9) females. Group one (1) was from Ndimoyo Palliative Care Centre, Group two (2) was from KCH Palliative Care Clinic and group three (3) was from Nkhoma Palliative Care Clinic. These participants had the following characteristics collected: age, gender, marital status, level of
education which could show the base of their knowledge, occupation which showed their source of income and religion showing their beliefs.

The results from the study indicate that out of 18 participants from the three study sites nine were males and the other nine were females. In addition, participants were asked to state their ages and out of 18 participants from the three study sites 10 were aged between 18 and 40 years. Six participants ranged between 41 to 50 years while two participants ranged between 51 to 60 years respectively. The results are in agreement to what Pindani (2008: 59) found in the study conducted in Malawi where HIV/AIDS cases occurred among the most economically productive age group of 20 to 45 years which could affect the financial needs.

Participants were asked their level of education using the four levels of schooling system in Malawi. Level one comprises of eight years of primary school education from standard one to eight in which upon completion learners receive a Primary School Leaving Certificate. Level two comprises of four years of secondary education from form one to form four after which learners are given a Malawi School Certificate of Education. Tertiary education comprises of university education in which college, technikon and various tertiary institutions where education and training is offered. Upon completion learners receive degrees, diplomas or certificates. Out of 18 participants interviewed from the three sites 10 had primary education, three participants had secondary education, two had tertiary education and the other three had no formal education. These results show that the majority of participants had primary education. Education is an important determinant of health since the higher the education level attained the more knowledgeable people are to diseases and the more the access to health care (MoH, 2010: 2).

In addition, participants were asked to state their marital status and out of 18 participants interviewed from the three sites the majority 14 were married while one was single. Two participants were widows and one was divorced. The results show that the majority of participants were married, which according to (Bowie, Kalilane, Cleary & Bowie, 2006: 4) would ensure household caring capacity. Pindani (2008):64) argues the majority of married couples makes chances for HIV spread high unless these families embrace fidelity.
Participants were also asked to state their occupation, and out of 18 participants interviewed from the three sites six of them were doing businesses, five of them did household farming, two (11.1%) of them were teachers and five of them were unemployed. The observation in this study is that the majority of participants are engaged in businesses, farming and other employments to support themselves.

Lastly, participants were asked about the religion that they belonged to and all of them belonged to different religions. Eight participants belonged to Christian religion while 10 were Muslims. Belonging to a religion has the potential to provide support to HIV/AIDS patients and enhance their social standing in the community (Muula, 2010: 125; Pindani, 2008: 66).

3.6 THEMES, CATEGORIES AND SUBCATEGORIES FROM HIV/AIDS PATIENTS

In addition to the data collected from palliative care nurses and primary caregivers, data was also collected from HIV/AIDS patients which was also organized into themes, categories and subcategories. Data was collected using individual in-depth interviews. Needs of HIV/AIDS patients was the main theme which emerged from the data as the central recurring idea found in text. From this theme five categories that are the grouped information with similar content emerged which pertained to the need for physical care from primary caregivers, need for quality health care services, need for knowledge, need for resources and need for support of HIV/AIDS patients. From the stated categories, subcategories emerged which are the subdivisions of the common differentiating characteristics and have been summarised in Table 3.3 below.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Categories</th>
<th>Sub-categories</th>
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<tbody>
<tr>
<td>Needs of PLWHA</td>
<td>1. Need for physical care from primary caregivers</td>
<td>• Need for assistance with hygiene</td>
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<tr>
<td></td>
<td></td>
<td>• Need for assistance with mobility and changing positions in bed</td>
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| 2. Need for quality health care services | • Need for assistance with wound care  
• The need to access all health care services at one clinic  
• The need for prompt treatment  
• The need for proper assistance from nurses |
|---|---|
| 3. Need for knowledge | • Primary caregivers to be taught about caring  
• Need for ART Knowledge  
• How to prevent parent to child transmission of HIV  
• Need knowledge on cancer of the cervix  
• Need breastfeeding knowledge  
• Knowledge of how to prevent infection of partners in sero-discordant partners |
| 4. Need for resources | • Need for infrastructure  
• Need for finances |
### 3.6.1 Category 1: Need for physical care from primary caregivers

Three sub-categories emerged from this category which pertain to the need for assistance with bathing, need for assistance with mobility and changing positions in bed and need for wound care. These needs were highlighted by participants due to their limitations for self-care due to the severity of their sickness; and their dependency on the primary caregivers for physical care. These sub-categories are discussed below:

#### 3.6.1.1 Subcategory 1: Need for assistance with hygiene

Some participants in this study expressed the need to be assisted with maintenance of hygiene such as bathing by primary caregivers during the period of the illness when they are too weak to wash themselves. They shared that bathing would ensure that they feel comfortable but also feel accepted by their primary caregivers. This was supported in the following excerpt:

“...*I fail to bath myself...I need help...my caregiver assists me with this...*”. (Participant 3, group 1 Ndimoyo Palliative Care Centre).

“...*she would bathe me which made me feel clean and accepted...*”. (Participant 2, group 1 Ndimoyo palliative Care Centre).

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<th>5. Need for support</th>
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<td>• Need for communication</td>
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<td>• Need for support from church</td>
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“...she assists me with bathing because I am weak...” (Participant 5, group 2 Nkhoma Palliative Care Clinic).

3.6.1.2 Subcategory 2: Need for assistance with mobility and changing positions in bed

Some participants in this study stated that their primary caregivers assist them with changing position to prevent development of pressure sores, and to avoid loss of sensation. Others also expressed the need for exercises, such as walking, with which their primary caregivers give assistance to build their strength. The description of immobility in this study is a significant finding. HIV/AIDS patients described mobility as an important dimension to quality of life. The above information is supported in the following quotations:

“When I was bedridden, my daughter used to turn me to prevent sores and numbness...this is important...” (Participant 1, group 2 Nkhoma Palliative Care Clinic).

“I was taught to exercise by walking in order to gain back my strength...I cannot walk alone without assistance...my caregiver helps me...” (Participant 3, group 2 Nkhoma Palliative Care Clinic)

“...at least I can walk now which is a very important feature in my life and for my survival...my caregiver has helped me in this...I could have been worse...”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

3.6.1.3 Subcategory 3: Need for assistance with wound care

Participants expressed that their primary caregivers and nurses assist them with caring for their sores, which brings comfort, prevents infection and enhances healing; many said that they would be unable to meet this need alone. The above information is supported in the following quotations:

“I have a wound on the back of my right leg...I fail to dress it myself...my wife does it and this brings comfort, she also tells me how the wound is looking”. (Participant 6, group 3 Nkhoma Palliative Care Clinic).
“...Nurses dress my wound every second day at the clinic...this is helping it to heal”. (Participant 4, group 1 Ndimooy Palliative Care Centre)

### 3.6.2 Category 2: Need for quality health care services

Three sub-categories emerged from this category. These sub-categories pertain to the need to access all health care services at one clinic, need for prompt treatment and need for positive attitude of nurses. Participants uttered that these needs affected their health due to time spent at the clinics, transport money and the quality of the services. These sub-categories are discussed below:

#### 3.6.2.1 Subcategory 1: The need for access to all health care services from one clinic

The participants in this study shared that they would benefit greatly from a one stop clinic for all their health care needs as this would ensure that they spend less time and money visiting different clinics for services. They wished that services like palliative care and ART provision be found at any of the clinics that they visited. They also wished for all clinics to provide uniform assistance in form of transport reimbursement for them not to miss the visits. This was evident in the following quotation:

“I wish that if I go to the ART clinic, I should get all the services without thinking of other appointments at the other clinics. May be palliative care should be found at the ART clinic and also when I go to the district hospital for vincrystine they should provide the other services like ART and even palliative care...” (Participant 1, group 1 Ndimooy Palliative Care Centre).

I only come here for palliative care especially for my painful legs and I get the ART from that other clinic...these are both government clinics but I have to come on different days...I wish that it should be one clinic...” (Participant 2, group 2 KCH).

“I get ART from the clinic next door and palliative care services from this clinic, I use different files and different days sometimes you are given the same medications twice...they could provide
the services at one clinic to treat all my needs at once...(Participant 4, group 3 Nkhoma palliative care clinic).

In addition, participants felt that accessing health care services from one clinic would ensure that continuity of care and monitoring of their conditions is achieved since they would be meeting the same nurses each time. This was expressed by the participants as follows:

“Firstly, I should be seeing the same nurses each time when I come here because I see different ones each time I have to explain myself each time ... to get proper help. I also have to explain myself at different clinics each time...”. (Participant 3 group B, KCH)

“Some of the medications are duplicated since I use different files at these clinics, they don’t have to work in isolation...” (Participant 4, group 1 Ndimoayo palliative care clinic).

“It is hard for nurses to monitor our progress at these different clinics...they need to work together...” (Participant 2, group 1 Ndimoayo palliative care clinic)

3.6.2.2 Subcategory 2: Need for prompt treatment
Participants mentioned the need for prompt treatment when they visit the clinics since they spent a lot of time waiting before receiving treatment at the clinics. The following comments from participants illustrate this:

“When I go to the government hospital firstly I spend the whole day there, the nurses come at their own time. I was there two days ago, I arrived at 8am and was only helped around 2pm and they do not even care”. (Participant 5, group 1 Ndimoayo Palliative Care Centre)

“There is normally only one nurse helping patients and they only use this room,... you spend hours before your turn comes. I wish that there were more nurses assisting us especially if you are in pain, you are not helped quickly...” (Participant 6, group 3 Nkhoma palliative care clinic).
“...they try their best to assist us, the nurses are so few and they take time to see each patient...there’s need for more nurses so that we get assisted quickly...” (Participant 2, group 1 Ndimoyo palliative care centre).

3.6.2.3 Subcategory 3: Need for proper assistance from nurses

Some of the participants expressed concern about the manner in which some nurses assisted them at some clinics. Participants commented that although some nurses in particular settings were considerate and caring, other nurses failed to treat them with respect. This was expressed in the following excerpts:

“...the way nurses treat you and talk to you says it all ... they also seem to be too busy when they are really not,... But some of them take nursing as a job and they do not care about the people...”. (Participant 4, group 1 Ndimoyo Palliative Care Centre)

“At the hospital, you get two kinds of nurses, some are nice and they really care and want to know what you are going through and help while others treat us to finish the queue. They shout anyhow, have a bad attitude towards us and I wish that they could know how we feel. But at the same place there were other nurses who are very nice and considerate....”. ((Participant 2 group B, KCH)

3.6.3 Category 3: Need for knowledge

Participants in this study mentioned the need for knowledge and six sub-categories emerged from this category. Participants uttered that need for this knowledge affected their health and the way they were cared for. These sub-categories are discussed below and pertain to:

- Primary caregivers to be trained in patient care
- The need for knowledge of ART,
- How to prevent parent to child transmission of HIV
- Knowledge of cancer of the cervix,
- Knowledge of breastfeeding,
- How to tailor sexual needs. Participants uttered that need for this knowledge affected their health and the way that they were cared for. These sub-categories are discussed below:
3.6.3.1 Subcategory 1: Primary caregivers to be trained in patient care
The HIV/AIDS patients shared that their primary caregivers need to be trained in patient care in order to assist them to better carry out their role. Lack of this knowledge negatively affected the care that participants were getting as expressed in the following statements:

“I also wish that my wife should be taught thoroughly about this condition and the caring that she is doing to have reasons than just doing it”. (Participant 2, Group 1 Ndimoyo Palliative Care Centre)

“...caregivers should also be trained ...to give the right care...real care is not provided”. (Participant 4, group 1 Ndimoyo Palliative Care Centre).

3.6.3.2 Subcategory 2: Need for ART knowledge
Lack of adequate ART knowledge was expressed by some participants in this study, many believed that increased knowledge could assist them to comply with their treatment regimen. Such lack of knowledge resulted in discontinuation of treatment for some patients when their condition improved. This was expressed by some participant in the following statements:

“I also need more information on ART...I stopped taking them for six months...I felt better”. (Participant 1, group 2 KCH Palliative Care Clinic).

“...I took ART for three months and was fine, but they say we should take them throughout...I don’t see the need...when I got very sick they told me that its because I stopped taking ART which does not make sense...” (Participant 4, group 3 Nkhoma Palliative Care Clinic).

“The clinics should teach us about ART on each visit...we tell each other wrong information and follow it...clinics need to teach us with proper explanations...” (Participant 1, group 2 KCH Palliative Care Clinic).
3.6.3.3 Subcategory 3: How to prevent parent to child transmission of HIV

The findings of the study show that some participants were in a marriage relationship where both partners were HIV positive, but wanted biological children. These participants expressed the need for understanding how to prevent infecting their unborn babies with HIV. They wished to have this knowledge in order to make an informed decision about having children. This has been expressed by the participants in the following quotations:

“The other need is educating me and my husband on issues of having more children which can be HIV free. My husband wants us to have a son and I am worried ...We need to be taught the right way so that we make the right decision and not infect the child”. (Participant 2, group 3 Nkhoma Palliative Care Clinic).

“I also need knowledge on sexual issues because I want to get married ...and have HIV free children” (Participant 3 group 2 KCH Palliative Care Clinic).

3.6.3.4 Subcategory 4: Need for knowledge of cervical cancer

Some HIV/AIDS patients in this study had cervical cancer while taking their ART, and wished to understand the relationship between HIV and cancer. They expressed that while on ART, they had not expected to be infected by other opportunistic infections or conditions such as cancer. These participants wished for their primary caregivers to have this knowledge as well in order to encourage screening and ensure that they receive proper care. This was expressed by the participants as follows:

“I used to think that while I am taking ART, I cannot get sick with cancer or things like that...I was told that I have cancer of the cervix and it is in advanced stage...what was I supposed to do before...They should also teach my sister so that she understands and gives me proper care, but also check her for this condition”. (Participant 3, group 3 Nkhoma Palliative Care Clinic).

“Nurses should teach patients on conditions such as cervical cancer and screen us, people are suffering with this condition....they only teach you when you are already sick...( Participant 1, Group 1 KCH Palliative care Clinic).
3.6.3.5 Subcategory 5: Need for breastfeeding knowledge

Two of the participants in this study shared that they had babies who needed breastfeeding, but that they received contradictory information from different nurses on breastfeeding which caused confusion and worry. As such they expressed a need for correct and consistent information from nurses on feeding options and durations for their babies. This information would assure them that they would prevent transmitting HIV to their babies through breast milk. This need has been expressed in the following quotations:

“... some nurses say that we should not breast feed at all like what I did with my last child, yet now others are saying that we should breast feed for six months...”. (Participant 2, group 3 Nkhoma Palliative Care Clinic).

“...nurses should tell us the right information because now our babies will be HIV positive because they say we should breastfeed them for two years...”. (Participant 4, group 3 Nkhoma Palliative Care Clinic).

3.6.3.6 Subcategory 6: Knowledge on preventing infection of partners in sero-discordant couples

The study findings reveal that some participants were in sero-discordant relationships and others wanted to be in marriage relationships. These participants lacked knowledge on sexual health that would enable them to modify their sexual needs and activities, and make the right decisions about sexual issues. The findings also highlight the need for teaching sero-discordant couples on methods to prevent infecting their partners. This has been expressed in the following quotations:

“...my wife is HIV negative and I don’t know how this happened...nurses should teach us and other families where one of us is HIV negative because I don’t want her to contract the condition”. (Participant 5, group 1 Ndimoyo Palliative Care Centre).

“I need knowledge on sexual issues because I want to get married and have children...but I don’t want to infect the child and my partner...they don’t teach us such things at the clinic, it is hard to ask such issues...”. (Participant 3, group 2 KCH Palliative Care Clinic).
3.6.4 Category 4: Need for resources
Numerous participants in this study mentioned the need for additional resources. Three sub-categories emerged from this category which pertains to infrastructure, financial need and nutritional need. These needs affected the health of participants and the way they were cared for. These sub-categories are discussed below:

3.6.4.1 Subcategory 1: Need for infrastructure
One participant mentioned the need for a palliative care ward where patients could rest after the first dosage of medications. Participants valued resting, especially when they are very sick. This was expressed by one participant in the following statement:

“I think our hospital should have a palliative care ward because sometimes I get very sick and here they give you medications and you have to go home without even resting a bit”. (Participant 1, group 2 KCH Palliative Care clinic)

3.6.4.2 Subcategory 2: Need for finances
Participants mentioned the need for money in order for them to afford paying for medications that are not free; transportation to the hospital and other significant costs such as school fees for the children. They believed that money was important for them to pay for their needs and take care of themselves. This need was expressed in the excerpts below:

“I also need money for transport to come to this clinic monthly for supply of medications”. (Participant 2, group 2 Nkhoma Palliative Care Clinic).

“ART are given for free but I have to pay for the other medications that I get here for my painful legs and sometimes I cannot afford and have to just stay in pain”. (Participant 5, group 3 Nkhoma Palliative Care Clinic).

“The other need is money for transport to the hospital and for buying medications. We are paying for everything recently except for ART. Now everything circles around money and the other thing
is that my children are going to school and I have to pay for school fees”. (Participant 6, group 3 Ndimoyo Palliative Care Clinic).

At the moment I spend most of my time visiting these clinics and I spend a lot of money on transport because I go on different days. It is only at palliative care clinic where they give us money for transport”. (Participant 1, group 1 Ndimoyo Palliative Care Centre)

Participants in this study wished for employment opportunities that would empower them to meet their own financial needs. They expressed a desire to still contribute to the needs of their families since they were now living longer. They suggested that this type of employment support could come from the government. This was mentioned in the following statements:

“I just need the government to help us who are HIV positive by offering jobs because most of us are not working and it is hard….. ”. (Participant 3, group 1 Ndimoyo Palliative Care Centre).

“The other thing that the hospitals or government could assist me with is helping me to find something else to do according to my condition. .....I still need to do things for myself and contribute to my family”. (Participant 5, group 1 Ndimoyo Palliative Care Centre).

“Then the other part is that the government should consider teaching us or creating jobs for us according to our condition since we are now living long”. (Participant 6, group 1 Ndimoyo Palliative Care Centre).

3.6.4.3 Subcategory 3: Need for good nutrition

Some participants highlighted the need for proper nutrition with all food groups; others shared the need for nutritional supplements. This need was expressed in the excerpts below:

“I wish for proper nutrition with all food groups...we don’t have this at home... ” (Participant 1, group 1 Ndimoyo Palliative Care Centre).
“I wish for the clinic to assist me with nutritional supplements like soya flour”. (Participant 6, group 2 KCH Palliative Care Clinic).

In addition, participants shared that they need money to afford buying food and other groceries. They mentioned that they have been taught about nourishing foods but that they could not afford to buy it. The following excerpts give evidence of this:

“The services at our district hospital and palliative care clinic are free but we still need money for food, transport and for groceries at home”. (Participant 5, group 1 Ndimoyo Palliative Care Clinic).

“...they told me about the food that I must eat but...I don’t have money to buy it ...”. (Participant 4, group 2 Nkhoma Palliative Care Clinic).

“I was told to eat different kinds of food to stay healthy...these foods are in many groups, I only remember beans, meat, eggs, soya flour, and vegetables... I wish that I could be provided with some of these because I cannot afford”. (Participant 3, group 1 Ndimoyo Palliative care Clinic).

“...I don’t have appetite and the foods that I like are expensive...”. (Participant 1, group 1 Ndimoyo palliative Care Centre).

3.6.5 Category 5: Need for support of HIV/AIDS PATIENTS
Support was mentioned by participants as a need which had six sub-categories. These sub-categories have been discussed below and pertained to the following:

- Support from nurses in the form of communication,
- Support from peers with the same condition,
- Community and family support
- Support from the church
- Support from the government.

3.6.5.1 Subcategory 1: Need for communication with nurses
Participants stated that they would benefit from regular communication via the phone with palliative care nurses. They were concerned that they do not have nurses contact numbers to call
for guidance and advice when they need health care services and support. Participants also shared that nurses contact numbers would assist them to check for their needs such as medications at the clinic and avoid travelling unnecessarily. The following excerpts illustrate this point:

“…I get sick often at night and sometimes I wish to have the phone number of someone that I could contact at the clinic for advice and management for such…” (Participant 5, group 1 Ndimoyo Palliative Care Centre).

“The other problem is that we are not given any contacts, so even if the medication has not arrived at the clinic we come all the way. I wish that a way of communication on such issues should be devised even to call for advice”. (Participant 6, group 3 Nkhoma Palliative Care Clinic).

“I also wish to have contacts in terms of phone numbers so that I could call because sometimes I come all the way when there was no need”. (Participant 5, group 2 KCH Palliative Care Clinic).

3.6.5.2 Subcategory 2: Need for peer support

Some participants in this study expressed that they felt alone during the course of their disease, and wished to engage with support group members who are also HIV positive. Their opinion was that there are benefits in joining support groups, but that they needed nurses’ assistance to form such groups. Some of the participants who already belonged to support groups articulated the benefits of joining support groups, such as encouraging and assisting each other; feeling accepted and having a forum to discuss problems and share knowledge. This was expressed in the following excerpts:

“The nurses could also help us to form a support group because at the moment I feel alone with this condition, maybe there are other people in the same situation in my community”. (Participant 3, Group 3 Ndimoyo Palliative Care Centre).

“I also joined the support group which helps me. At the hospital they do teach me what they know but they do not know what happens in my life at home so the support group helps…all of us in that group are HIV positive and we really encourage each other. We treat each other like family and
you feel that you are not suffering alone...”. (Participant 2, group 1 Ndimoyo Palliative Care Centre).

3.6.3 Subcategory 3: Need for support from community members

Some participants stated that they needed greater support from community members as a means of reducing the stigma they experienced in their own community. Their view was that the lack of HIV knowledge in their community was causing community members to fear HIV, and consequently reject and stigmatize them. As such, the participants mentioned that they do not reveal their HIV status with community members and HIV is rarely discussed openly. This was expressed in the following excerpts:

“My community is just fine, the only thing is that people have heard about HIV but lack the knowledge...This has led to HIV not being freely discussed at home and if people know that you are HIV positive they talk about you and stigmatize you. That is why I did not want to disclose my status. ...I fear rejection...”. (Participant 5, group 3 Nkhoma palliative care clinic).

“...because I could not walk they used to tell my wife that she is living with a corpse... now it is better but my community does not associate with me”. (Participant 6, group 1 Ndimoyo Palliative Care Centre).

“The village members do not involve me in any village activities, even my wife’s friends stopped visiting her...I wish that things could change”. (Participant 1, group 3 Nkhoma palliative care clinic).

Although some participants felt stigmatized, others felt accepted by their communities. One participant expressed this as follows:

“I also have friends in my community who have accepted me and my condition and they visit me and assist me with needs”. (Participant 4, group 2 KCH Palliative Care Clinic).
3.6.5.4 Subcategory 4: Need for stigma eradication among family members and nurses

Some HIV/AIDS patients in this study described feelings of depression and sadness due to what they were facing from their family members and nurses at some clinics. Their opinion was that their sense of wellbeing would improve greatly if they were treated well and were not stigmatised by their families and nurses. This was expressed in the following excerpts:

“*My brothers call me names such as a walking corpse... and do not visit me...it is not good and makes me sad...my sister has accepted my condition and she assists me...people need knowledge to change...*”. (Participant 1, group 1 Ndimoyo Palliative Care Centre).

...because I could not walk, they (my family) used to tell my wife that she is living with a corpse...if they could be taught about this condition, this would stop because it is not good... (Participant 6, group 1 Ndimoyo Palliative Care Centre).

“I sometimes face stigma from nurses at the ART clinic...one nurse once said to me, was I there when you contracted your disease? So please don’t trouble me with your complaints...this need to change especially from people who have the knowledge of our condition...”. (Participant 4, group 1 Ndimoyo palliative care clinic).

3.6.5.5 Subcategory 5: Need for support from church

In addition to support from the community and family members, some participants mentioned that they were encouraged by visits from church leaders and members, while others noted that such support would improve their sense of wellbeing. This was expressed by two participants as follows:

“*Sometimes they call our church leader to visit me and pray for me which encourages me*”. (Participant 4, group 2 KCH Palliative Care Clinic).

“The other support that I need at times is prayers from church and other people.....”. (Participant 3, group 2 Nkhoma Palliative Care Clinic).
3.7 SUMMARY
This chapter has discussed the findings of data collected through qualitative research methods from three groups of participants namely: palliative care nurses, HIV/AIDS patients and their primary caregivers from Ndimoyo palliative care centre, KCH palliative care clinic and Nkhoma palliative care clinic in Malawi. Individual interviews were used for collecting data from HIV/AIDS patients and primary caregivers and focus group interviews were used for collecting data from palliative care nurses. The theme identified during individual interviews with HIV/AIDS patients was needs of HIV/AIDS patients with categories as follows: Physical care, quality health care services, knowledge, resources and support. For primary caregivers, the theme identified was needs of primary caregivers with the following categories: training, resources and support. The theme identified during focus group discussions with palliative care nurses was needs of palliative care nurses with categories as follows: training, resources, support and guidelines. The next chapter discusses the key findings of the study and existing literature on this topic.
CHAPTER FOUR

DISCUSSION OF THE FINDINGS OF THE FIRST PHASE OF THE STUDY

4.1 INTRODUCTION

This chapter discusses the findings of the first phase of the study. These findings are the basis of the guidelines developed in chapter six. As already discussed in chapter three, the study had three groups of participants namely: palliative care nurses, primary caregivers and HIV/AIDS patients. Focus group discussions were utilized during data collection for palliative care nurses, and individual interviews were used to collect data from HIV/AIDS patients and primary caregivers.

The themes identified during focus group discussions with palliative care nurses were needs of palliative care nurses with the following categories of needs: training, resources, support and guidelines. The themes identified during individual interviews with primary caregivers were needs of primary care givers with categories of needs as follows: training, resources and support. Finally, the themes identified during individual interviews with HIV/AIDS patients were needs of HIV/AIDS patients with the highlighted needs in the following categories: physical care, quality health care services, knowledge, resources and support. The discussions are focused on the categories from the three groups which are discussed collaboratively and their relationship to literature.

4.2 NEED FOR TRAINING AND KNOWLEDGE

The study revealed that the palliative care nurses, primary caregivers and HIV/AIDS patients lacked knowledge necessary to carry out their respective duties and manage the challenges of the illness. The knowledge areas differed from the three groups and are discussed below:

4.2.1 PALLIATIVE CARE NURSES’ NEED FOR TRAINING

The palliative care nurses mentioned that they lacked knowledge and skills in palliative care and needed training as more knowledgeable nurses would improve the quality of care for the patients. Palliative care nurses attributed this lack of knowledge to the type of training attended in Malawi. The Malawi-trained nurses mentioned that their training was inadequate; had limited content and lacked a
practical component than those that trained in Uganda. Palliative care nurses expressed their need in this regard as discussed below:

“...Here in Malawi they provide one week training and no practical component so nurses lack knowledge and this is affecting palliative care provision in Malawi”, (Group 1, Ndimoyo Palliative Care Centre).

The palliative care nurses recognized that this lack of knowledge negatively affected the care of the patients and support they provided to primary caregivers. The nurses need for knowledge and skills is emphasized by Bergdahl, Wikstrom and Andershed (2007: 756-757) that they needed the skills and expertise in technical aspects of nursing in order to have self–confidence, go beyond routines and for safety of the patient but also provision of quality care. Palliative care nurse participants shared that their lack of knowledge is also attributed to lack of palliative care component in the curriculum during their initial nursing training. Similar to this study, Callahan, Breakwell and Suhayda (2011: S15) found that the common reason for lack of palliative care knowledge was lack of palliative care content in academic curricula. Furthermore, the study conducted by Ferrell, Virani, Paice, Malloy and Dahlin (2010: 40) concluded that lack of proper education is an obstacle to nurses as they strive to deliver palliative care since they can only practice what they know. Results of this study and literature have provided evidence that proper training of nurses in palliative care is the basis of acquiring knowledge needed for quality patient care and support of caregivers and lack of this knowledge has a negative impact on the knowledge of the primary caregivers and HIV/AIDS patients.

4.2.2 NEED FOR TRAINING OF PRIMARY CAREGIVERS

The primary caregivers disclosed that they lacked knowledge of their patients’ condition and provision of proper care. They attributed this lack of knowledge to lack of training and information from nurses in preparation for their role. The lack of knowledge in primary caregivers in this study is in agreement to findings of a study conducted by Kang’ethe (2010: 197) where primary caregivers lacked basic information on caregiver role due to lack of training which compromised the effectiveness of care giving. Primary caregivers in this study attributed this lack of knowledge to lack of training from nurses in their role as evidenced by this expression:
“I wish that I get trained to know how to care for my mother in a proper way….If nurses could teach me about what I am supposed to do because sometimes I don’t know what I am doing and it is frustrating”. (Participant 1, group 2 KCH Palliative care clinic and Participant 2, group 3 Nkhoma Palliative care Clinic).

The results of this study are similar to what Hudson, Trauer, Lobb, Zordan, Williams, Quinn, Summers and Thomas (2012: 10) found where healthcare professionals were required to share knowledge with primary caregivers for proper care to be provided to patients but in reality this was not happening. It is vital that caregivers understand the nature of the patient’s illness, the range and scope of service provision and their own role and competencies in palliation which could only happen if they get trained by nurses (Docherty, Owens, Asadi-Lari, Petchey, Williams & Carter, 2008: 154). Proper training of primary caregivers is vital to increase their knowledge and enhance coping and wellbeing of patients. Some authors have noted that it is possible for health care workers to improve the sense of preparedness for family caregivers in their role through training and reduce their unmet needs and also enhance the wellbeing of patients and empower them in decision making (Stajduhar, Funk, Jakobsson & Ohlen, 2010: 222; Hudson, et al., 2012: 11). However, Pavlish and Ceronsky (2009: 404) state that nurses need clinical expertise, honesty and family orientation to manage their roles of teaching, caring, coordinating, advocating and mobilizing of resources.

The primary caregiver’s also attributed their lack of knowledge to limited interaction between them and the palliative care nurses. Primary caregivers indicated that HIV/AIDS patients are in constant contact with palliative care nurses at the clinic but this interaction is also needed with them for knowledge sharing and support in order for them to provide the required care. Various authors concluded that limited interaction between primary caregivers and health care professionals leads to inadequate knowledge of primary caregivers, lack of access to resources and lack of support (Hudson et al., 2012:10; Hudson & Payne, 2011: 867). Furthermore, other studies concluded that health care professionals should know the needs of primary caregivers and provide education and information on their role (Candy, Jones, Drake, Leurent & King, 2011: 6; Hudson & Payne, 2011: 867; Payne, Hudson, Grande, Oliviere, Tishelman, Pleschberger, Firth, Ewing, Hawker & Kerr, 2010: 286-287; Lee, Li, Jiraphongsa & Rotheram-Borus, 2010: 61). Results of this study and literature have proved
that it is vital for primary caregivers to be equipped with knowledge through contact and training by nurses and be able to manage their patient’s needs appropriately.

4.2.3 NEED FOR KNOWLEDGE OF HIV/AIDS PATIENTS

HIV/AIDS patients in this study indicated that they also needed knowledge on different aspects of their health. This group of participants expressed their wish to have primary caregivers trained so that they can in turn receive proper and adequate care. This was evidenced by the following quotation:

“...caregivers should also be trained and supported to give the right care...real care is not provided”. (Participant 4, group 1 Ndimoyo Palliative Care Centre).

Zukoski, Thorburn and Stroud (2011: 1507) state that seeking and obtaining information is a critical component of health literacy and survival of HIV/AIDS patients which should not be ignored. HIV/AIDS patients in this study also indicated that they needed adequate knowledge of ART for better understanding and importance of adherence. Although ART have dramatically altered the course of HIV disease into a chronic disease, lack of adherence has led to retroviral resistance in most patients (Eldred & Malitz, 2007: 1-2). Scajiu, Rveis and Selwyn (2009: 1534) noted that ART adherence is interfered with chaotic patient life circumstances and side effects, and called for health care workers to teach the caregivers on patients’ medications so that social support is provided and influence adherent behavior. Lack of this knowledge in the patient and caregiver could affect the patients’ survival due to problems that could develop. Fehringer, Bastos, Massard, Maia, Pilotto and Kerrigan (2006: 638) noted that many HIV/AIDS patients across the globe have survived by being adherent to ART while lack of adherence leads to treatment failure and development of drug-resistant strains of HIV, hence the need to teach HIV/AIDS patients on this aspect. Molassiotis, Morris and Trueman (2007: 370) added that educating the patient and building a trusting relationship between the patient and clinician contribute to patients being adherent to ART. It is evident from the study results and literature that nurses should teach patients for them to acquire knowledge and improve their health behaviors’.

This study also noted that HIV/AIDS patients lacked knowledge on prevention of HIV infection in a discordant relationship. According to British HIV Association guidelines of 2008 cited in Fakoya, Lamba, Mackie, Nandwani, Brown, Bernard, Gilling-Smith, Lacey, Sherr, Claydon, Wallage and
Gazzard (2008: 683) HIV positive men and women, and their partners as well as sero-discordant couples should be counselled on risk reduction strategies for natural conception in order to know the risks of HIV transmission and those planning to have children are supposed to receive pre-conceptual counselling on all the conception options, including HIV transmission risks so that they can make an informed choice. In addition, the reproductive clinical care for HIV/AIDS patients should address contraceptive use, planned pregnancy, and protected sex to improve patient empowerment in decision making (Malta, Todd, Stibich, Gracia, Pacheco & Bastos, 2010: 480). It is therefore evident that interventions aiming at addressing reproductive and sexual health needs of HIV/AIDS patients should be made available for each patient to improve their quality of life and proper decision making.

4.3 NEED FOR RESOURCES
The findings of this study revealed that the palliative care nurses, HIV/AIDS patients and primary caregivers lacked resources that were in care provision to patients. Shortage of clinical resources in palliative care centres according to participants affected quality of care. The palliative care nurses in this study mentioned the need for drugs in order to provide proper care to patients while the primary caregivers stated the need for clinical resources such as gloves for their personal protection, cotton wool, and bandages but also wound cleaning solutions, sanitary pads and medications for the patients’ care. In addition, HIV/AIDS patients also mentioned the need for medications and good nutrition. These needs have been discussed as follows:

4.3.1 PALLIATIVE CARE NURSES’ NEED FOR RESOURCES
Palliative care nurses in this study mentioned that they lacked adequate space which affected privacy of patients. This was stated as follows:

“The challenge is privacy because the same room is used as a consultation room and also storage of patients files and most of the times people will be in and out fetching things from this room,...compromises privacy”. (Group 1, Ndimoyo Palliative Care Centre).

The need for maintaining physical and verbal privacy was emphasized by some authors who stated that privacy should include the body and also space to ensure the maintenance of auditory privacy and confidentiality and delivery of high-quality care which shows that patients and relatives are valued (Lin, Watson & Tsai, 2012: 174; Baillie & Gallagher, 2011: 338). In addition, Brereton, Gardiner,
Gott, Ingleton, Barnes and Carroll (2012: 982) concluded that the environment can profoundly affect the health, wellbeing, independence and quality of patient’s life which needs attention at all times. Palliative care nurses should therefore ensure that their working environment ensures privacy and confidentiality of the patient and primary caregiver at all times.

Palliative care nurses further mentioned the need for clinical resources such as drugs which affected care since some clinics would run out of stock while others required patients to pay. A participant stated this as follows:

“...most of the times we have no drugs...we sometimes run out of drugs to help patients in pain like morphine, so this affects us ...we then start giving alternatives like ibuprofen which are not as effective...lack of medicinal resources affects care given by caregivers at home...”. Group 3, Nkhoma Palliative Care Clinic).

Studies by Grant, Brown, Leng, Bettega and Murray (2011: 10); Mosoiu, Ryan, Joranson and Garthwaite (2006: 2110) noted that oral morphine was a vital and often new intervention which greatly benefited patients, and helped staff to deliver and know they were providing effective pain relief. The same authors mentioned that in African countries minimal resources are provided since the health care system focus on preventive, curative and maternal health services allocating minimal or no resources to supportive and palliative care (Grant et al, 2011: 10). As such, shortage of drugs like morphine jeopardized patients’ pain control in this study and the role played by primary caregivers at home. Some authors found that drug shortages interfere with patient care since it leads to selection of alternative therapy, which may not be as effective and may also increase risk of adverse effects (McLaughlin, Kotis, Thomson, Harrison, Fennessy, Postelnick & Sheetz, 2013: 783; Kaakeh, Sweet, Reilly, Bush, DeLoach, Higgins, Clark & Stevenson, 2011: e20). Health care systems should therefore ensure that adequate clinical resources including drugs such as morphine are available at all times for proper care of patients.

Besides the need for clinical resources, the study findings revealed that human resource was a great need in palliative care since other sites such as KCH and Nkhoma had only one nurse working permanently in palliative care. This was stated as follows:
“The nurses that are here work in different wards and only come here if there is no body since normally there is only one nurse allocated permanently in palliative care clinic...It would actually be better if there would be three nurses every day since this clinic is run by palliative care nurses.... it affects the type of counselling because you want to see other patients as well” (Group 2, KCH Palliative Care Clinic, (Group 3, Nkhoma Palliative Care Clinic).

Evidence from literature indicates that adequate nurse staffing improves health outcomes of patients, results in fewer inpatient days, complications and death, and also promotes patient safety and quality of health care (Kane, Shamliyan, Mueller, Duval, & Wilt, 2007: 1196). According to Callaghan, Ford and Schneider (2010:8), Sub-Saharan Africa suffers from the world's most pronounced crisis in human resources for health which is intensified by the HIV/AIDS pandemic. In addition Schell, Rankin, Chipungu, Rankin and Weiller (2011: 66) state that nurses are the largest group of health care providers in Malawi performing most of the health care for its citizens at a ratio of 37 nurses per 100,000 people. Furthermore, Bemelmans, van den Akker, Pasulani, Tayub, Hermann, Mwagomba, Jalasi, Chiomba, Ford and Philips, (2011: 14) observed that in Malawi severe health worker shortage is attributable to both an inadequate supply of trained health workers and poor retention of staff within the health system due to low remuneration, high workload, poor working conditions, illness and death. The study results as well as literature have proved the importance of adequate human resource which needs to be addressed at all times in the clinical care to achieve quality patient care.

4.3.2 HIV/AIDS PATIENTS NEED FOR RESOURCES

Interestingly, the need for space stated by palliative care nurses was also mentioned by HIV/AIDS patients as an important health resource in this study. HIV/AIDS patients mentioned that they needed space in form of a day ward for them to rest after taking treatment at the clinic. One participant stated this need as follows:

“I think our hospital should have a palliative care ward because sometimes I come here while very sick and here they give medications and you have to go home without even resting a bit”, Participant 1, group 2 KCH Palliative Care Clinic). The need for a day ward for patients to rest was also mentioned by palliative care nurses in the following statement:
“I wish we had a room like a day ward where patients can rest after getting the first dosage of analgesics before going home”. (Group 2, KCH Palliative Care Clinic). Similarly, lack of adequate space in this study was mentioned as a compromising factor in efforts of quality care delivery and patients’ access to services in a study conducted by (Kabore, Bloem, Etheredge, Obiero, Wanless, Doykos, Ntsekhe, Mtshali, Afrikaner, Sayed, Bostwelelo, Hani, Moshabesha, Kalaka, Mameja, Zwane, Shongwe, Mtshali, Mohr, Smuts, & Tiam, 2010:582). It is therefore evident that adequate space in palliative care should be provided to ensure that patients are provided with quality care.

For HIV/AIDS patients in this study, the need for financial resources to assist them with health needs was also a concern. They mentioned the need for financial resources to assist them with health needs. They mentioned the need for money to buy medications, food, pay school fees for their children and for transportation to the hospital. This was expressed in the following excerpts:

“The other need is money for transport to the hospital and for buying medications. We are paying for everything recently except for ART. Now everything circles around money and the other thing is that my children are going to school and I have to pay for school fees” ... we still need money for food...and for groceries at home”. (Participant 5, group 1 Ndimoyo Palliative Care Clinic) and Participant 6, group 3 Ndimoyo Palliative Care Clinic).

Agbonyitor (2009: 307); Zerfu, Yaya, Dagne, Deribe, Ruisenor-Escudero & Biadgilign (2012: 11) also found that everything around HIV illness was tied to money because of the need to pay for children’s school fees, pay for hospital bills, transport and buy food. According to Barnett and Whiteside cited in United Childrens Fund (UNICEF) (2007: 209); Miller and Tsoka (2012: 204), many PLWHA experience financial difficulties because of reduced household labour supply and increased demand for healthcare and nutrition and the cost of travelling to clinics, which could be a barrier to treatment. Furthermore, Kipp, Tindyebwa, Rubaale, Karamagi and Bajenja (2007: 859) highlighted that the financial burden in HIV/AIDS care is worsened in affected families since this condition mostly affects the sexually active age groups in their economic prime time when they are breadwinners and the death of younger adults in the families pose a social and economic challenge for the affected families. Loewenson (2007: S86 - S87) mentioned that financial support to primary caregivers could be achieved by using financial loans like what women use in Uganda. To achieve quality patient care, the
need for financial resources for patients and primary caregivers should be identified and addressed appropriately since HIV care depends on resources.

In addition to financial resources, the need for proper nutrition was mentioned as a great need for HIV/AIDS patients in this study. As one of them said: “I wish for proper nutrition with all food groups...” (Participant 1, group 1 Ndimoyo Palliative Care Centre). Various authors noted that poor nutrition in HIV patients was due to food shortages and this affected nutritional status and progression of HIV (Oguntibeju, van den Heever & Schalkwyk, 2007:4327; Ahoua, Umutoni, Huerga, Minetti, Szumilin, Balkan, Olson, Nicholas & Pujades-Rodriguez, 2011:14; Fan, Kuo, Kao, Morisky & Chen (2011:295). In addition, Tiyou, Belachew, Alemseged and Biadgilign (2012:11) found that lack of access to sufficient quantities of nutritious food affects the success of ART and is mainly due to lower education status, low food diversity and average family monthly income. Kalichman, Cherry, Amaral, White, Kalichman, Pope, Swetsze, Jones & Macy, 2010:633; Duran, Almeida, Segurado and Jaime, 2008:346-350; Ahoua et al (2011:14) believe that increasing access to food and improving nutrition for HIV/AIDS patients could have a significant impact on their health and should therefore be integrated into the care and treatment package of the patients. Despite the acknowledgement of the value of proper nutrition and suggestions made to improve nutritional status for HIV/AIDS patients, this study shows that HIV/AIDS patients lacked proper nutrition which could affect their health outcome.

HIV/AIDS patients mentioned that most of the times the clinics do not have clinical resources such as gloves and bandages and primary caregivers have to buy these resources themselves which was expensive and they did not have money. Kang’ethe (2010: 199) noted that primary caregivers are not provided with protective equipment which causes them to worry about contracting HIV and are also neglected by the government and their community in resource provision. The findings of this study were also found by Majumdar and Mazaleni (2010: 13) that primary caregivers lacked money to buy gloves, dressings, toiletries and sheets and mentioned that donations of such resources from the government would assist in supporting caregivers. Without provision of resources, primary caregivers fail to perform their roles effectively; therefore interventions should be in place for resource provision in palliative care for provision of quality health care to the patients.
4.3.3 PRIMARY CAREGIVERS NEED FOR RESOURCES
The need for drugs in this study was also mentioned by primary caregivers in a different way from palliative care nurses. Primary caregivers from CHAM hospitals mentioned the need for all medications to be provided for free since patients could not pay for the drugs themselves and it became the primary caregivers’ responsibility to pay and sometimes patients had to endure the pain due to lack of money to buy the necessary drugs. The following comments support this: “...I also wish that nurses could give all the other medications for free like what they do with ART because it is expensive to buy and Kamuzu Central hospital is far”...these patients cannot pay for themselves”.... (Participant 1, group 3 Nkhoma Palliative Care Clinic). “ART are given for free but I have to pay for the other medications that I get here for my painful legs and sometimes I cannot afford and have to just stay in pain”. (Participant 5, group 3 Nkhoma Palliative Care Clinic).

Several authors mentioned that palliative care encompasses effective management of pain and lack of access to pain relief medications affects pain management (Callahan et al, (2012: s19; Wilson, 2011: 1017; Lucey, McQuillan, MacCallion, Corrigan, Flynn & Connaire, 2008: 188). It was evident from the research study and literature that availability of analgesics could assist nurses to manage patients’ pain effectively.

Although primary caregivers continued to provide care to HIV/AIDS patients, findings of the study revealed that they lacked financial and clinical resources such as gloves. The findings were consistent to what Kang’ethe (2010: 199) found that primary caregivers are not provided with protective equipment such as gloves which is an occupational hazard causing them to worry about contracting HIV. The study conducted by Majumdar and Mazaleni (2010: 13) also found that caregivers lacked money to buy gloves, dressings, toiletries, sheets and condoms and suggested that such resources should be provided by health care workers. Furthermore, the need for financial support was mentioned by caregivers as a need. This need was similar to findings of a study by Vithayachockitikhun (2006: 124) where primary caregivers of HIV/AIDS patients experienced enormous burdens related to financial limitations and insufficient support which worsened with duration of care giving. Loewenson (2007) added that financial support to most household comes from family members and are linked to death of a family member but also
community support such as burial societies and saving clubs and suggested that using loans is an innovation to improve economy of caregivers.

4.4 NEED FOR SUPPORT

This study revealed that the palliative care nurses, HIV/AIDS patients and primary caregivers lacked support in different forms. In addition, the three groups of participants mentioned the need to support primary caregivers. The need for support has been discussed as follows:

4.4.1 Need to support palliative care nurses

Palliative care nurses in this study mentioned that they lacked support from peers and experienced colleagues who would ensure that they cope, perform their roles better and also prevent burn-out. Pereira, Fonseca and Carvalho (2011: 317) found that palliative care provision led to health care providers experience physical, psychological and emotional exhaustion, with occurrence of burnout, suffering in silence without professional support. According to Jayasuriya, Whittaker, Halim and Matineau (2012: 12) relationship and support from colleagues is one of the strong facets of job satisfaction and motivation for nurses. Palliative care nurses in this study mentioned that mentorship in their role would improve knowledge, patient care and enhance professional growth. Other authors mentioned that the value of mentorship in nursing is to bridge the gap between theory and practice since nurses are expected to be competent in skills from the outset of work with obvious implications for professional accountability which requires mentorship (Myall, Levett-Jones & Lathlean, 2008: 1840; Tinson, Axe & Berry, 2011: 219). As such, participants wished to be mentored in their role since mentoring proved to be a positive strategy for supporting nurses and increases quality of care and productivity (Wallen, Mitchell, Melnyk, Fineout-Overholt, Miller-Davis, Yates & Hasting, 2010: 2768). It is clear from this study and literature that support from peers and experienced colleagues through mentorship would increase knowledge and improve quality of patient care.

Palliative care nurses in this study also mentioned the need for support from nursing management to ensure that adequate staffing is available. This was mentioned as follows: “...the nursing side of management is not supportive that is why we have problems with staffing and environment which is affecting our care...”. (Group 2, KCH Palliative Care Clinic).
Some authors observed that the quality of relationship between the health workers’ and their line manager influences the health workers’ perceptions of the work climate, either positively or negatively and commitment to supporting learning are support measures in the clinical environment (Muldowney & McKee, 2011: 206; Jayasuriya et al., 2012: 12). Laschinger, Gilbert, Smith and Leslie (2010: 5) observed that the key aspect of the nurse manager’s role is to create conditions that empower nurses to provide the best possible care to patients within an environment that fosters professional practice and effective working relationships. In agreement Grindel (2006: 126) found that empowered nurses can effect change, make a difference in the workplace environment, are committed to the organization and support colleagues. Support from management is therefore vital for palliative care needs to be addressed and quality care achievement as demonstrated in this study and literature.

Although care was provided to patients, findings from palliative care nurses revealed that they lacked a guide on providing specific care to patients which made them to use different sources of information to provide care. They also expressed concern over limitations of the current guidelines as being too general and lacking primary caregivers support component. This was expressed as follows: “...the guidelines are also too general; I wish that they could deal with specific issues separately... I wish for extra information to compliment these guidelines for proper care of patients. ... There’s also need to support caregivers but even if we wanted to support the caregivers, we do not have a proper guide of how we should do it so this should be the starting point...we cannot apply knowledge from the other guidelines because they are too general”, (Group 2, KCH Palliative Care Clinic).

Different authors agree that tools such as guidelines could assist health professionals in demonstrating that their support for primary caregivers is systematic and effective but also facilitate in improvement of patient care and ensure safe practice (Hudson, Remedios, Zordan, Thomas, Clifton, Crewdson, Hall, Trauer, Bolleter, Clarke & Bauld, 2012: 697 & 701; Amosu, Degun, Makinde, Thomas & Babalola, 2011: 256). It was evident from the research study and literature that guidelines are important tools for quality patient care and proper support of primary caregivers which was lacking for palliative care nurses in this study.
4.4.2 Need to support primary caregivers

The study revealed that the support needs of primary caregivers are different from palliative care nurses and HIV/AIDS patients. The study discussed the support needed by primary caregivers where the need for nurses’ contacts numbers, nurses to involve them in the care, respite support and support from community members and the government was mentioned. Primary caregivers in this study mentioned that they needed respite support so that they could rest from the role and do personal things such as shopping. This was expressed by one participant in the following quotation: “The only thing that I need is relief sometimes so that I can go to the garden or the shops...”, (Participant 1, group 1 Ndimoyo Palliative Care Clinic).

The studies conducted by Funk, Stajduhar, Aoun, Grande and Todd (2010:597); Majumdar and Mazaleni (2010: 13) showed that providing care can negatively impact physical health of the caregiver and is a source of stress which needs respite care to maintain stamina. Other authors added that most caregivers for HIV patients are elderly and taking on this role brings negative implications on their economy, health and well-being since they also care for the patients dependants often with no support (Ssengonzi, 2009: 310; Boon, James, Ruiter, van den Borne, Williams & Reddy, 2010: 399). In addition, Hudson and Payne (2011: 866) mentioned that the care system should lessen caregiver burden by providing periods of respite through physical rest, social interaction, education, recreation or employment outside the home. Based on the results of this study and literature, it was evident that the caregiver role can impact negatively on their physical health and economical stand, as such support should be provided physically, economically and also through provision of respite.

In addition to respite support, the primary caregivers mentioned that they needed contact numbers for nurses to be able to communicate with them if they need information and guidance. This was expressed as follows: “I wish that I could have nurses’ phone numbers to call from home if my son gets very sick or I want to ask for information,” (Participant 1, group 1 Ndimoyo Palliative Care Clinic).

Hudson and Payne (2011: 866); Docherty et al. (2008: 166) in their studies have shown that poor communication and lack of information between caregivers and health care professionals could affect quality of patient care and that communication is a key issue in facilitating proper care (Hudson &
Payne, 2011: 866; Docherty et al., 2008: 166). Studies conducted by Allen, Mbonye, Seeley, Birungi, Wolff, Coutinho & Jaffar (2011: 530); Scajiu et al., (2009: 1528) suggested that healthcare teams may enhance dialogue with patients and caregivers in order to create therapeutic decisions to accommodate the priorities and values of the patient and their families by having telephone numbers to call for advice. Communication between caregivers and health care workers is vital for proper care provision to patients as evidenced in this study and literature.

Findings of the study conducted by Docherty et al, (2008: 166) found that communication between caregivers and health professionals was inadequate and yet it was a key in determining the adequacy of information provision and caregiver understanding. In addition Scajiu et al, (2009:1528) suggested that healthcare teams may enhance dialog with patients and caregivers in order to create therapeutic decisions to accommodate the priorities and values of the patient and their family which required involving both parties. Involving caregivers in the care ensures that continuity of care is achieved at home.

Furthermore, primary caregivers stated that they needed nurses to involve them in the care when the patient is admitted so that they continue providing the expected quality care for the patient at home. This was uttered as follows: “I just wish that nurses should involve us in the care of the patient especially in the hospital. The nurses and doctors want to talk to the patient only without involving me and at home I don’t know what to do..., “ (Participant 5, group 3 Nkhoma Palliative Care Clinic).

4.4.3 Need to support HIV/AIDS patients

The need for nurses’ contact details was also expressed by the HIV/AIDS patients in this study. This was evidenced in the following statement: “I get sick often at night and sometimes I wish to have the phone number of someone that I could contact at the clinic for advice and management for such... “, (Participant 5, group 1 Ndimoyo Palliative Care Clinic).

In a systematic review conducted by van Velthoven, Car, Car and Atun (2012:5), it was observed that telephonic interventions offered the potential to improve health of PLWHA cost-effectively and reduce the burden on affected people and health systems, and also improve access to health
care services even in resource limited health care setting. McIlfatrick (2007:84) found that the need for improved coordination and communication around a 24-hour period was identified to benefit continuity of care and reduce inappropriate hospital admissions; and that provision of phone numbers provided emotional support to both patients and their caregivers. The results from this study and literature confirm the need for having telephone contacts from nurses for the HIV/AIDS patients and their primary caregivers as a support measure for meeting their needs.

4.5 NEED FOR PHYSICAL CARE FOR HIV/AIDS PATIENTS

HIV/AIDS patients articulated their need for physical care which included bathing, mobility, wound care and changing their position in bed. This was indicated by one participant in the following statement: “...I struggle to walk and fail to bath myself... I fell at home and have a wound on my right leg... I cannot dress it myself... my wife does it,” (Participant 6, group 3 Nkhoma Palliative Care Clinic).

The above quotations indicate a self-care deficit in HIV/AIDS patients, which is similar to findings of the study by Gaidhane, Zahiruddin, Waghmare, Zodpey, Goyal and Johrapurkar (2008: 1098) where performing activities of daily living such as washing, caring for body parts, toileting, dressing, eating, drinking, and looking after one’s health were regarded as important determinants of health relating to quality of life. Due to self care limitations of HIV/AIDS patients, the study conducted by Vithayachockitikhun (2006: 125) found that caregivers took responsibilities of providing basic and physical care but also providing assistance with cooking, giving medicine, physical exercise and wound care. Furthermore, a study conducted by Fan, et al., (2011: 287-302) found that patients who had more advanced disease in stage three and four as determined by the WHO clinical stage and CD4 count had lower physical health and vitality limiting their self-care roles than patients in early stages. Due to physical limitations placed on the HIV/AIDS patients by the illness Majumdar and Mazaleni (2010:13) in their South African study noted that performing the tasks of day-to-day living such as maintaining hygiene, eating and dressing presented a challenge that required caregivers to provide assistance.
4.6 NEED FOR QUALITY HEALTH CARE SERVICES FOR HIV/AIDS PATIENTS

HIV/AIDS patients in this study also expressed the need for support in the form of quality health care services. Although care was provided to HIV/AIDS patients from different clinics, findings of the study revealed that participants could benefit from integration of health care services. This was shared by one participant as follows: “I wish that if I go to the ART clinic, I should get all the services without thinking of other appointments at the other clinics. May be palliative care should be found at the ART clinic and also when I go to the district hospital for vincristine they should provide the other services like ART and even palliative care. At the moment I spend most of my time visiting these clinics and I spend a lot of money on transport because I go on different days. It is only at palliative care clinic where they give us money for transport” (Participant 1, group 1 Ndimoyo Palliative Care Clinic).

In studies conducted by Orner, Cooper, Myer, Zweigenthal, Bekker and Moodley (2008: 1220); Myer, Rabkin, Abrams, Rosenfield and Els-Sadr (2005: 138) it was found that integration and linking of services for HIV/AIDS patients was beneficial for quality of health care delivery to patients and sustained improvement. Kohli, Purohit, Karve, Bhalerao, Karvande, Rangan, Reddy, Paranjape and Sahay (2012: 1) recommended that care interventions for PLWHA should not operate in isolation but be embedded into spheres of health facility, community, workplace and the environment, and also linked up with the family in order to mitigate the impact of the disease. The results from this study and literature confirm the need for having integrated health care services for achievement of quality care to patients.

HIV/AIDS patients in this study also mentioned that accessing their health care services required time because they were not treated promptly. An example was voiced by one participant as follows: “When I go to the hospital firstly I spend the whole day there, the nurses come at their own time. I was there two days ago, I arrived at 8am and was only helped around 2pm...” (Participant 5, group 1 Ndimoyo Palliative Care Centre). This is congruent to the findings of a study by Orner et al., (2008:1220) where HIV positive women wanted prompt, courteous, competent, thorough and appropriate care. Quality health care services with prompt treatment are necessary for the survival of HIV/AIDS patients.
Participants shared that although some of them were treated well at the health care facilities, others experienced bad attitude from the nurses which needs to change as it could affect the health and survival of HIV/AIDS patients. A study conducted by Hassan and Wahsheh (2011: 774) also found that nurses had a negative attitude towards HIV patients which related to fear of contagion, outcome of the disease, direct care, education and counseling due to their lack of knowledge. In addition a study conducted by (Lam, Chan & Thayala, 2011: 2106) showed more prejudice from nurses and changed practice behaviours after knowing the patients HIV status.

The findings from this study have revealed that quality care to HIV/AIDS patients by palliative care nurses at the clinics and continuity of care by primary caregivers at home are vital for the survival and quality of life for these patients. This study has also shown that although palliative care nurses have different needs, they are the right people to provide support to primary caregivers and ensure that proper care is provided to HIV/AIDS patients. As such guidelines developed in chapter six are meant to offer direction to palliative care nurses on how they could support primary caregivers of HIV/AIDS patients. The guidelines would also guide palliative care nurses to meet their own needs and ensure that quality care to HIV/AIDS patients is achieved.

4.7 Summary
This chapter discussed the key findings of the study from three groups of participants namely: palliative care nurses, PLWHA and primary caregivers that are the basis of the guidelines developed in chapter six. Focus group discussions were utilized during data collection from palliative care nurses and individual interviews were used to collect data from PLWHA and primary caregivers. The next chapter discussed an integrative literature review.
5.1 INTRODUCTION

In phase one of the study, research findings and literature control were presented where support emerges as a need from palliative care nurses, primary caregivers and HIV/AIDS patient. HIV/AIDS patients are now looked after by primary caregivers at home who need support from nurses to ensure that quality care and quality of life is improved. As such the purpose of this study is to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. For better understanding of the guidelines, the researcher synthesized existing evidence regarding ‘support’ to primary caregivers in palliative care through an integrative review in this phase. Support to primary caregivers in palliative care has been described as the most important strategy for improving quality of patient lives (Hudson & Payne, 2011: 864). Supporting caregivers of HIV/AIDS patients has the potential to meet their needs and reduce the high degree of stress that they face which would improve their quality of lives and that of their patients (Feng, Feng, Chen, Lu, Ko & Chen, 2009: 488).

Caregivers throughout the world represent a backbone to health care delivery since they assume complex amount of care that were once provided by nurses (Stajduhar, et al., 2010: 574). In addition Payne and Grande (2010:579) recognized that caregivers are essential in providing physical care, emotional, social, financial resources and advocacy for the patient and require support to perform their roles better and maintain their optimal health. The same authors state that the caring role exposes caregivers to different stresses. Aga, Kylma and Nikkonen (2009: 244) identified social and cultural factors which influenced care giving that related to religious beliefs, economic issues, education, social stigma and discrimination. Furthermore, the care giving role is demanding and exhausting which can affect the caregiver’s mental health and limit her ability in the caring provision. As such, caregivers’ needs have to be assessed and supported in this role to provide proper care to patients and still maintain their own health. This integrative
review adopted Whittemore and Knafl’s (2005: 546 - 553) method as a guide which has been discussed in chapter two.

5.2 LITERATURE SEARCH PROCESS

Using predefined search terms MEDLINE (EBSCO), Cochrane and CINAHL were searched for studies published between January 2004 and May 2014 and reference list from relevant articles were cross-checked. The following journals were also hand searched for relevant articles between 2004 and 2014: Palliative Medicine, BMJ Supportive and palliative care, International Journal of Palliative Nursing and BMC palliative care. Palliative care, caregiver, support and HIV/AIDS patients were used as search terms (see Table 5.1).

<table>
<thead>
<tr>
<th>TABLE 5.1: SEARCH TERMS USED IN ELECTRONIC DATABASE SEARCH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care</td>
</tr>
<tr>
<td>Caregiver</td>
</tr>
<tr>
<td>Support</td>
</tr>
<tr>
<td>HIV/AIDS patients</td>
</tr>
</tbody>
</table>

Support to primary caregivers was used as a key word and all studies included were in English and had documented the method clearly. A rigorous approach to the search process identified 200 studies which were examined for relevance to the topic. Studies had to discuss support to caregivers for chronic conditions which included HIV. Studies focussing on the specific support to caregivers and palliative care were included. The exclusion criteria consisted of studies focussing on health professionals and not palliative care, studies written in other languages other than English, studies having unclear methodology and written prior to 2004. Of the 200 studies, four articles met the criteria to answer the research question under study and were selected for review.

5.3 Relevant articles

The first article was a randomized controlled trial conducted by Candy et al. (2011). The second study was a systematic review conducted by Hudson and Payne (2011). The third study was an integrative review conducted by Payne et al. (2010). The fourth study used data from a randomized controlled family intervention trial conducted by Lee et al. (2010). Data was
analyzed using manual coding and coding sheets were prepared for this purpose. The content of the research was described using the following variables: aim of the research, definitions of support, description of caregivers and research recommendations. Each study was coded individually for all variables which resulted in matrix of information. Themes were then identified and synthesized.

5.4 FINDINGS

The summary of the four research studies that were identified has been provided individually in Table 5.2 as follows:

**TABLE 5.2: SUMMARY OF THE RESEARCHES ON SUPPORT OF PRIMARY CAREGIVERS**

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Aims/objectives</th>
<th>Method</th>
<th>Relevant findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candy, Jones, Drake, Leurent &amp; King</td>
<td>2011</td>
<td>To assess interventions for supporting informal caregivers of patients in the terminal phase of a disease.</td>
<td>Randomised controlled trial</td>
<td>It is evident that direct support to caregivers helps them cope emotionally, cope in their role and improve quality of their life. Practitioners should enquire about caregiver needs and offer supportive interventions.</td>
</tr>
<tr>
<td>Hudson &amp; Payne</td>
<td>2011</td>
<td>To outline an informed account of family caregiving within the context of palliative care and to propose an agenda for the future.</td>
<td>Systematic reviews</td>
<td>Multiple reasons exist on need to support caregivers of palliative care patients. There’s need for improved information, training, and other support services for caregivers in order for them to take greater control of their circumstances.</td>
</tr>
</tbody>
</table>
5.5 THEMES ON SUPPORT OF CAREGIVERS

The four studies in the sample focussed on support to caregivers and the following four recurring themes were identified from the synthesized data:

(a) Caregivers’ self description of support

(b) Impact of caring on caregivers

(c) Support needs of caregivers

(d) Interventions for improving support to caregivers

5.5.1 Theme one: Caregivers’ self description of support

All four studies described the caregiver’s self description of support. Candy et al. (2011: 6) reported that caregivers described support as practical and provided information on domestic and
respite services aiming to increase coping skills and wellbeing which would be provided by counselling and advice on caring. In addition Lee et al. (2010: 57) in their study described caregiver support as access to network resources and being provided with psychological support to improve the wellbeing of caregivers. Furthermore, Hudson and Payne (2011: 865) described caregivers’ support as provision of resources, education and information, flexible health care appointments for their patients, financial security and respite support.

5.5.2 Theme two: Impact of caring role on caregivers

The four articles also examined the component of the impact of caring for patients on caregivers. Lee et al. (2010: 58) in their study reported that caregivers’ role exposes them to experiences of adverse effects on the psychological well-being leading to social isolation, psychological distress and poor quality of life. In addition Payne et al. (2010: 242-243); Hudson and Payne (2011: 865) state that this role could lead to carers neglecting their own physical health, affect family communication leading to conflicts, impact on work and finances of carers leading to economic problems, straining family structures but also have a social impact leaving carers isolated with little opportunity for recreation and social activities. Furthermore, Candy et al. (2011: 6) stated that this role could be extremely stressful both mentally and physically without supportive interventions.

5.5.3 Theme three: Support needs of caregivers

Candy et al. (2011: 2) expressed that family and friends are the main providers of care which can generate mental and physical stress for the caregivers’ needing supportive interventions. Lee et al. (2010: 57) also indicated that caregivers’ need support since they assume this role without preparation and might require further adjustments in the family, work and social commitments. Payne et al. (2010: 240) said that the caring role is physically, psychologically, socially and financially demanding and carers occupy an ambiguous role needing support to cope and perform better. Hudson and Payne (2011: 865) stated that caregivers’ have unmet needs, assume numerous roles without training and information hence the need to be supported. Two selected studies identified the support needs of caregivers. Payne et al. (2010: 242) identified the support needs of caregivers and interventions to meet the needs. The authors concluded that carers need psychological support, information, assistance with personal, nursing and medical care of the
patient, out of hours and night support, respite care and financial help (Payne et al. 2010: 286). In addition, the second study conducted by Hudson and Payne (2011: 867) acknowledged the need for education to prepare caregivers’ in their role, access to resources in order to assist them to maintain psychosocial wellbeing and need for support from health care professionals. Candy et al. (2011: 2) reported that health care practitioners should inquire about needs of caregivers and the benefit of supporting them. Hudson and Payne (2011: 865) stated that proper support of caregivers’ could lead to improvement of patients’ well-being through proper care provision, make a remarkable economic contribution to health care but also ensure that the caregiver has positive outcomes.

5.5.4 Theme four: Interventions for improving support to caregivers

Intervention for support of caregivers featured in three studies. Candy et al. (2011: 2) in their study explored interventions for supporting informal caregivers of patients in the terminal phase of a disease. It was evident that interventions that directly support the caregiver assist them to cope emotionally, cope in their caring role and improve their quality of life (Candy et al. 2011: 3). The second study conducted by Payne et al. (2010) recommended interventions that would support caregivers which included psychological and emotional support, information, assistance with personal, nursing and medical care of the patient, out of hours and night support but also financial support. The third study conducted by Hudson and Payne (2011: 866) proposed that care systems could provide the following supportive interventions for caregivers: information and education, resources, respite, caregiver financial security and bereavement support. The same authors added that other interventions for improving support of caregivers is provision of training to health care professionals who may be lacking knowledge of the supportive interventions, provision of resources and funding for such support to be achieved (Hudson & Payne, 2010).

5.6 SUMMARY OF THE SELECTED ARTICLES

Four studies were selected in this integrated review. All the authors in the four studies agreed that there is need to supporting caregivers in their role; as such it is imperative that they get support according to their needs. The first study was a randomized controlled trial conducted by Candy et al. (2011) which explored interventions for supporting informal caregivers of patients
in the terminal phase of a disease. The results revealed that care giving involve considerable stresses such as physical, psychological and economical which require a range of supportive programmes for caregivers. In addition the second study conducted by Hudson and Payne (2011) revealed the reasons and importance of supporting caregivers and proposed how the carers could be supported.

The third study was an integrative literature review conducted by Payne et al. (2010) which had two parts. The results revealed that caregiver role affects their physical, social, mental health and has impact on family structure and financial resources. The study made recommendations for improving support of carers. Furthermore, the fourth study conducted by Lee et al. (2010) used data from a randomized controlled family intervention trial which looked at caregiver burden of family members of persons living with HIV. The results showed that caregivers’ role led them to have poor quality of life and that support contributed to positive caregivers’ quality of life.

5.7 SUMMARY
This chapter has discussed about the integrative review undertaken to synthesize existing evidence regarding support to primary caregivers in palliative care. It adopted Whittemore and Knafl’s (2005) process as a guide. Different databases were searched to identify relevant articles and search terms were utilized. Support to caregivers in palliative care and HIV care has been described as the most important strategy for improving care of patients and improving the quality of caregiver lives. This support would ensure that the caregiver needs are met which would have a positive impact on caring.
CHAPTER SIX: PHASE 3
DEVELOPMENT AND DESCRIPTION OF GUIDELINES FOR NURSES TO SUPPORT PRIMARY CAREGIVERS OF HIV/AIDS PATIENTS IN PALLIATIVE CARE IN MALAWI

6.1 INTRODUCTION
The previous chapter synthesized existing evidence regarding support to primary caregivers in palliative care through an integrative literature review. The aim of this chapter is to discuss the development and description of guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.

Guidelines are instructions that are developed and could be used to assist in making a decision or forming an opinion based on proper evidence from research (Oxford Advanced Learners dictionary, 2005: 709). The guidelines put forward here represent goals that palliative care nurses should strive to attain, as opposed to minimal or lowest acceptable practices. These guidelines should not substitute one set of services (palliative) for another set of services (curative), but rather create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered and support of primary caregivers is achieved.

The researcher was guided by the adapted, modified and integrated Evidence-Based Guidelines Development (EBGD) and National Institute for Health and Clinical Excellence (NICE) process during guidelines development which has been described in detail in chapter two. The researcher utilised four steps of the modified, adapted and integrated EBGD and NICE process which are presented schematically in Figure 6.1 below.
Step one
1. Select experts/stakeholders
2. Review baseline data from the integrative review and the current study results
3. Identify key aspects to be included

Step two
1. Explore the current goals and
2. Formulate the clinical question
3. Write the consultation draft of the proposed guidelines based on reviewed evidence and study

Step three
1. Distribute draft of guidelines to experts/stakeholders for comments
2. Review the comments from experts/stakeholders and write a final draft of guidelines based on the comments received and distribute to the experts/stakeholders again

Step four
1. Review their comments then write and submit the final guidelines to experts/stakeholders for final approval
2. Prepare the final guidelines

Figure 6.1: The Evidence-Based Guidelines Development (EBGD) and National Institute for Health and Clinical Excellence (NICE) process utilised during guidelines development
The researcher’s use of the EBGD and NICE methods ensured that the draft guidelines be developed based on study results and an integrative literature review from chapter four using a formulated clinical question where key aspects that are included were spelled out. The four steps of EBGD and NICE process were followed in sequence and are discussed concurrently as follows:

6.1.1 Step one of the EBGD and NICE process
Step one of the EBGD and NICE process involved the following: selection of experts/stakeholders to advice and review the guidelines; review of the baseline data from the current study results; discussion of key findings and the integrative review and identification of key aspects to be included in the guidelines (The Evidence-Based Care Group, 2006 and NICE, 2006). The researcher carried out the processes in step one as follows:

6.1.1.1 Selection of experts/stakeholders
The term experts or stakeholders refer to people who are well informed about a particular subject. This could include health care professionals, patients, carers and organisations that are able to provide input into the guidelines according to the content of the scope (NICE, 2006:18). The World Health Organization (WHO) recommends that an expert team should have equitable geographical representation, gender balance, multidisciplinary with a minimum of 8–12 individuals representing stakeholders which should include professionals, disease experts, primary care/public health, end users, and patients to represent different trends of thought, approaches and practical experiences (Fretheim et al. 2006: 4). Chilemba (2013: 116) added that experts should be knowledgeable about the topic or have sufficient experience regarding the issue under discussion. Furthermore, experts provide an accessible source of information that can be quickly harnessed to gain opinion (Baker, et al. 2006: 61).

In this study, nursing professionals, clinical officers, nurse educators, policy makers and managers, patients and caregivers who were conversant with issues of supporting primary caregivers in palliative care for HIV/AIDS patients were consulted. The researcher selected
thirteen experts based on their work experience in palliative care and HIV and AIDS care who could attest to their expertise. The researcher also selected people working at academic institutions who have knowledge of the issue at hand; nurses working in palliative care units; policy makers; Palliative Care Association of Malawi (PACAM) representative and Nurses and Midwives Council of Malawi representative who deal with the issue at hand. This was a purposive sample selected based on their work experience and knowledge of the subject as discussed in chapter two. The researcher initially contacted some experts using the telephone, and electronically with other experts but also through meetings with other experts based on their location which has been discussed in step two of the process. Table 6.1 provides a summary of descriptive information of the members of the expert panel that were involved in refinement of the guidelines, their positions, qualifications and experiences.

Table 6.1: Descriptive information of experts

<table>
<thead>
<tr>
<th>NO</th>
<th>POSITION</th>
<th>QUALIFICATIONS</th>
<th>EXPERIENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Senior Lecturer</td>
<td>Registered Nurse, PhD</td>
<td>Experience in guidelines development; theoretical and clinical teaching of nurses. Experience in HIV care and management.</td>
</tr>
<tr>
<td>2</td>
<td>Country Manager of Palliative Care Association in Malawi (PACAM)</td>
<td>Clinical Officer, BSc palliative care</td>
<td>Coordinator and manager of palliative care training, care and provision in Malawi. Coordinates all activities and care in relation to palliative care in Malawi since 2005 when PACAM was established.</td>
</tr>
<tr>
<td>3</td>
<td>Lecturer in Community Health Nursing</td>
<td>Registered Nurse, Masters of Public Health</td>
<td>Ten years experience in community health nursing; involved in palliative care and Home-based care teaching, care and activities in the community.</td>
</tr>
<tr>
<td>4</td>
<td>Lecturer and Clinical educator</td>
<td>Registered Nurse, BSC Nursing, MSc student in Nursing education</td>
<td>More than five years experience in clinical teaching in general wards and palliative care clinics.</td>
</tr>
<tr>
<td>5</td>
<td>Lecturer and Clinical educator (Voluntary Service Overseas (VSO))</td>
<td>Registered Nurse, BSC Nursing, Diploma in Palliative care</td>
<td>Has 15 years clinical ward experience. Has worked in Specialist Palliative care since 2006 in UK and then Oncology unit in Malawi at a Central hospital for two years.</td>
</tr>
<tr>
<td></td>
<td>Position</td>
<td>Education and Experience</td>
<td>Experience Details</td>
</tr>
<tr>
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<td>--------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>6</td>
<td>Senior Lecturer</td>
<td>MSc Community health, BSc honours, Dip Public Health Nursing and Midwifery</td>
<td>Has worked in community setting for 30 years, and is involved in curriculum, guidelines and module development for BSc and MSc in nursing which includes palliative care.</td>
</tr>
<tr>
<td>7</td>
<td>Ministry of Health, HIV/AIDS care and Management Unit</td>
<td>Clinical Officer, Diploma in HIV/AIDS management and trainer of trainers in HIV/AIDS management</td>
<td>More than 10 years hands on experience in HIV/AIDS management; trainer in HIV/AIDS management and is also involved in policy making.</td>
</tr>
<tr>
<td>8</td>
<td>Monitoring and evaluation Officer, Nurses and Midwives Council of Malawi.</td>
<td>Registered Nurse, BSc Nursing and Masters in Nursing management</td>
<td>Monitors and evaluates nursing processes and training, formulation of guidelines, curriculum development in Malawi; also involved in policy making.</td>
</tr>
<tr>
<td>9</td>
<td>Non-governmental organization (NGO) palliative care centre founder and coordinator</td>
<td>Registered Nurse, BSc Nursing, Diploma in palliative care</td>
<td>Has more than 10 years hands on experience working in palliative care in United Kingdom (UK); and is a founder of a NGO palliative care centre in Malawi and has been managing it for ten years. Trainer in palliative care provision.</td>
</tr>
<tr>
<td>10</td>
<td>Palliative care Nurse and coordinator at a Central Hospital</td>
<td>Registered Nurse, Diploma in palliative care and Diploma in HIV/AIDS management</td>
<td>Fifteen years experience in clinical nursing care, eight years hands-on experience in palliative care and HIV management.</td>
</tr>
<tr>
<td>11</td>
<td>Palliative care patient</td>
<td>Primary school teacher</td>
<td>HIV positive and palliative care patient for four years</td>
</tr>
<tr>
<td>12</td>
<td>Primary caregiver</td>
<td>Housewife</td>
<td>Primary caregiver for three years</td>
</tr>
<tr>
<td>13</td>
<td>Country Community and Home-based care coordinator, Ministry of Health, Community home based care and palliative care department</td>
<td>Registered Nurse, MSc in community Nursing care, trainer of trainers in home-based care and palliative care</td>
<td>More than 10 years hands on experience in clinical nursing at a facility level, community and home-based care settings. Trainer of trainers in home based care and palliative care course and involved in policy making.</td>
</tr>
</tbody>
</table>
6.1.1.2 Review of baseline data as a background to guidelines development

The Malawi Ministry of Health developed palliative care guidelines in 2011, which recommended that primary caregivers should be supported by health care workers to achieve quality patient care although these guidelines do not advise on how to support caregivers (MoH, 2011a). In addition, the first phase of this study revealed needs of primary caregivers, HIV/AIDS patients and palliative care nurses where the need for guidelines by nurses was mentioned in order for them to support primary caregivers in their needs and achieve quality patient care. This prompted the development of the guidelines put forward in this chapter.

Furthermore, the researcher conducted an integrative literature review that included studies conducted by (Candy et al. 2011; Hudson & Payne, 2011; Payne et al. 2010; Lee et al. 2010. The integrative literature review showed that the caring role exposed caregivers to challenging experiences and circumstances that had adverse effects on their psychological well-being leading to social isolation, psychological distress and poor quality of life and that of their patients (Payne et al. 2010). In addition, this role affected the physical health of carers, and led to straining and conflict in the family, and had an impact on work and finances of carers leading to economic problems (Hudson & Payne, 2011). The integrative review also concluded that carers need support in the following forms: education; information on their role and responsibilities; psychological support; assistance with personal; nursing and medical care of the patient; out of hours and night support; respite care; resources. The review also showed that health care professionals should know the needs of primary caregivers to be able to support them. It was evident from the first phase of the study and integrative review that interventions that directly support the caregiver assist them to cope physically, psychologically, socially and emotionally in their caring role and improve their quality of life.

Based on the research findings from the current study and the integrative literature review, the researcher recommended that nurses support primary caregivers according to their needs. The primary caregivers in this study are the individuals who care for HIV/AIDS patients at home; these were often a relative or family member, friend, child, parent or a community member as revealed in the research findings and the integrative literature review.
Providing support to primary caregivers of HIV/AIDS patients is vital and could result in quality care delivery and enhance quality of life for patients hence the need for developing the guidelines for nurses. Health care professionals should aim at improving the quality of patients’ lives and primary caregivers through proper care and support at all times by using these guidelines, with monitoring and evaluation as an on-going process.

6.1.2 STEP TWO OF THE EBGD AND NICE PROCESS
Step two of the EBGD and NICE process involved exploring the current goals; formulation of the clinical question; and writing of the consultation draft of the guidelines based on the reviewed evidence and study results. The processes in step two were discussed in detail below:

6.1.2.1 EXPLORING THE CURRENT GOALS
Dickoff, James and Wiedenbach (1968: 420) suggest that guidelines should be formulated by considering the goal of the guide. The main recommendation from the study results, discussion of key findings and the integrative review was that primary caregivers should be supported by nurses to achieve quality care for HIV/AIDS patients. For this support to be achieved, nurses needed a guide that would advise them on how to provide and ensure consistent support to HIV/AIDS patients in Malawi. As such, the current goal was for nurses to support primary caregivers of HIV/AIDS patients in palliative care to achieve proper care of patients and a better quality of life.

6.1.2.2 FORMULATION OF THE CLINICAL QUESTION
The current goal of developing the guidelines led to the formulation of the following question: “What are the guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care? This question was intended to direct the developing of the guidelines to achieve the goal of improving quality of life for HIV/AIDS patients and support of primary caregivers. The question needs to reflect the agent who would perform the activity, recipient of the activity, the context where the activity would take place and the dynamics that would motivate the nurses and health care team and also the procedure itself (Dickoff, et al., 1968: 420).
In this study, nurses working in palliative care and any health-care setting with HIV/AIDS patients would be the main agents. However, agents in the guidelines would also include other health care workers who look after HIV/AIDS patients or make decisions. The recipients of this support would be the primary caregivers of HIV/AIDS patients in palliative care in Malawi for proper care of the HIV/AIDS patients. The support of primary caregivers of HIV/AIDS patients would take place in all health care settings where nurses interact with the primary caregivers. These settings may include palliative care clinics, ART clinics, at home and in the hospital wards. The use of the guidelines for support of primary caregivers of HIV/AIDS patients in palliative care would be motivated by the nursing and general health care principle of providing quality nursing and health care to HIV/AIDS patients.

6.1.2.3 CONSULTATION DRAFT OF THE GUIDELINES

The consultation draft of the guidelines was formulated by the researcher from the study findings and integrative review and was sent to the two research supervisors for input and approval before distributing it to the experts. The approved draft of guidelines reflected the four key areas which are the findings of the study. Findings of the study revealed the following needs from palliative care nurses: need for knowledge, need for resources, need for support and need for guidelines. These needs affected care of the HIV/AIDS patients who also experienced different needs and support of the primary caregivers in their caring role. The primary care givers shared the following needs: need for training in their role and education on the patient’s condition, need for financial assistance and clinical resources and need for support from nurses, community members, other relatives and the government. Findings showed that the needs of primary caregivers affected patient care and quality of patients’ lives. Furthermore, the HIV/AIDS patients shared the following needs: need for physical care such as bathing, wound care and mobility, need for quality health care services where one-stop clinic, prompt treatment and proper assistance from nurses were mentioned, need for knowledge of their treatment, prevention of HIV transmission, prevention of cancer and knowledge of breastfeeding were mentioned as needs and need for resources and support in different forms.

In addition to these needs, the integrative review also indicated interventions that would support primary caregivers in the following forms: information and education, clinical and financial
resources, assistance with patient care, respite and bereavement support. From these needs the draft of guidelines was formulated (see appendix S for the drafted guidelines) reflecting the following four areas:

- need for knowledge of primary caregivers, HIV/AIDS patients and palliative care nurses;
- need for resources of palliative care nurses, primary caregivers and HIV/AIDS patients;
- need for physical care and quality health care services for HIV/AIDS patients and
- need for support of primary caregivers, HIV/AIDS patients and palliative care nurses.

6.1.2.4 Management of the consultation with experts

Before consultations, the researcher had a list of prospective experts who would contribute valuable information on the guidelines, and obtained their contact details through colleagues working in the field and the Ministry of Health. The initial communication was conducted telephonically with some experts while with some it was conducted via e-mail (electronically) and for others face to face meetings were arranged until agreement was reached on participating or not. This was the feasible way of communicating due to geographical distribution of participants and the busy schedule of some such that arranging one meeting was not possible and this was done individually. During this initial contact a brief introduction was given about the study and the role that experts would have. For experts who agreed to take part, information on the study was shared and needed clarifications were made telephonically, electronically and through face-to-face meetings.

After this initial contact, the researcher sent the draft of the guidelines via e-mail (electronically) or provided a hard copy to the experts with a brief introduction about the study, the need for support guidelines and their role in refining the guidelines. The role of the experts was to give input to the developed draft of guidelines and the criteria to be followed was provided. A two weeks period was agreed upon with experts as the deadline for getting feedback, although this needed to be extended for almost all the experts. The researcher maintained continuous communication with the experts electronically and through individual meetings until the process of refining the guidelines was completed. The process of refining guidelines took eleven weeks in total.
6.1.3 STEP THREE OF THE EBGD AND NICE PROCESS

Step three of the EBGD and NICE process involved distribution of the draft guidelines to experts for comments, then the researcher reviewed the comments and wrote a final draft of guidelines based on the comments received and distributed this to the experts again for final comments. The process of comments and refinement is discussed in detail below:

6.1.3.1 Process of refining the drafted guidelines

The drafted guidelines were developed by the researcher and refined by the experts. Due to geographical distribution of the experts, group meetings were not practically possible; as such the draft guidelines were distributed and commented on individually in all the three rounds. The researcher communicated to the experts through e-mails (electronically) and telephone and the draft guidelines were sent by e-mail to some experts and also handed to others as preferred after obtaining informed consent. The first draft of guidelines was shared with the thirteen experts who were purposefully selected. In this round the researcher included the criteria that experts could use for their input which included the following: importance of the guidelines, accessibility and generality, language used and simplicity, clarity and applicability and any other information that was important for the guidelines. The researcher set a period of two weeks for review and comments to allow the experts adequate time.

After two weeks of waiting for feedback, only six of the thirteen experts had provided comments prompting the researcher to send a reminder to the remaining experts. After a further two weeks passed, four more experts had provided their comments; the researcher again sent another reminder to the remaining three experts, who eventually submitted their comments after two months. With guidance from research supervisors, the researcher subsequently collated and incorporated the input of the experts into the guidelines, and circulated a second draft to the experts again and most of them responded within a period of three weeks. Literature advocates for a range of two to four rounds to achieve consensus on the issues by the experts (Chilemba, 2013: 116). This study adopted the three rounds design according to EBGD and NICE process and consensus was reached through this process.
The researcher shared with the experts the objective of the study and results of the integrative literature review as a basis for the draft guidelines in the first round. In this round, all the experts agreed that these guidelines were important and that the content was necessary. Some experts commented on noted repetitions in some areas, and suggested that information be grouped and sub-topics were also suggested. Some areas were perceived to be lacking clarity and needed rationale and action points as suggested and some experts’ added information on areas that they felt were missing. Suggestions were also made on including diagrams for clarity of information such as pain assessment scales and management guide. The researcher incorporated the comments that were suggested. Broad comments and information on the subject area were also provided by experts in this round.

After summarizing responses from experts in the first round and incorporating them in the guidelines, the researcher initiated the second round with guidance from the two supervisors. A second draft of the guidelines was sent to the experts again for reconsideration of new suggested information or change of previous position (Pechak & Black, 2014: 524). The second round assisted the experts to see the input of their fellow experts and decide to agree or refine the information. Eleven experts returned the guidelines and had no additional comments except for grouping the content while two experts gave suggestions on the layout and editorial corrections on the guidelines. All the experts agreed on information from their fellow experts and refined the grouping of the information with no disagreement on the content as such consensus was reached in this round and no consensus form was used.

6.1.4 STEP FOUR OF THE EBGD AND NICE PROCESS

Step four of the EBGD and NICE process involved preparation of the third and final draft of the guidelines and circulating them to the experts again for approval and any additional comments. Upon approval from the experts, the researcher prepared the final guidelines. This process is detailed below:

The researcher prepared the final draft of the guidelines in this third round and provided them to the experts again for approval and any comments; the experts gave no additional input on the guidelines and approved the final draft of the guidelines. In consultation with research
supervisors, it was determined that no further input was necessary and consensus was reached. The final guidelines were then given to the experts and only six of them gave written response while the other seven gave no written comments but indicated verbally that the guidelines need no further input. The six experts evaluated the guidelines using critical reflection and six domains of Appraisal of Guidelines for Research and Evaluation (AGREE) (see appendix T for the evaluation guide). The critical reflection guide checked for clarity, simplicity, generality, accessibility and importance of the guidelines (Chinn & Kramer, 2008: 246 – 248). The AGREE domains checked for the scope and purpose of the guidelines, stakeholder involvement, rigour, clarity and presentation, applicability and editorial independence. The researcher compared the feedback received from the experts and with guidance from research supervisors deemed that consensus has been reached. Consensus of opinion refers to agreement among expert participants about issues under discussion (Boulkedid, Abdoul, Loustau, Sibony & Alberti, 2011: 6). The evaluation process has been discussed further under appraisal of guidelines. The researcher then prepared the final guidelines.

6.2 THE REFINED GUIDELINES
The guidelines were sent to experts for their input and refinement. The refined and final guidelines were grouped into the five key areas pertaining to support of primary caregivers of HIV/AIDS patients. After the guidelines were formulated by the researcher with guidance from the two supervisors, the experts gave their input and refined the guidelines. The guidelines included the following key areas: ethics and caring, resource management, holistic approach in palliative care, improving knowledge in palliative care and monitoring, evaluation and reporting. These key areas ensured that the needs of palliative care nurses, primary caregivers and HIV/AIDS patients are reflected and met. These are reflected in the figure 6.2 below:
In ethics and caring, nurses would be guided to ensure that they support primary caregivers through open communication. It would also guide nurses to ensure that patients rights, cultural beliefs, provision of conducive environment and involving multidisciplinary team is achieved at all times. In resource management, the guidelines would support nurses to ensure that needs for resources in palliative care nurses, patients and primary caregivers are known and met. This
would ensure that nurses are guided to achieve adequate staffing in palliative care and provision of clinical resources in palliative care and for primary caregivers and proper management of resources.

The guidelines would also support palliative care nurses in improving knowledge in palliative care, since knowledgeable nurses would provide proper care to patients and impart knowledge and skills to patients, family members and primary caregivers. The guidelines would guide nurses to ensure that their training needs are met through continuous professional development, adequate training and mentorship.

In holistic approach in palliative care, the guidelines aim to guide nurses to ensure that they support primary caregivers in meeting the physical, psychosocial and spiritual needs of the patient utilising the multidisciplinary team, coordinating the services and provision of quality health care services to the patients through integration of services and a proper referral system.

In monitoring, evaluation and reporting, the guidelines aim to support nurses to ensure that proper records are kept of their care and support; availability of clear indicators for monitoring services and provision of monthly and quarterly reports for continuity of patient care and support primary caregivers.

**6.3 THE APPROVED GUIDELINES BY EXPERTS**

Experts approved guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. The guidelines have been developed with rationale and actions to be carried out by nurses based on the five anchors and are discussed in detail below:

**6.3.1 ETHICS AND CARING**

**Guideline 1: Nurses are to ensure that patients rights and ethics of caring are followed at all times for HIV/AIDS patients and the primary caregivers**

**Rationale**
Each patient and primary caregiver is unique, with his or her own beliefs, needs, strengths and values. Palliative care nurses work is to understand and protect patient rights in a culturally sensitive manner and protect patients’ dignity in order for proper care to be provided. Palliative care nurses establish trust and ensures that open communication exists between them, patients, primary caregivers and those who make decisions for the patients’ based on the patients’ condition and inform the patient on their rights.

**Actions**

This is achieved in the following ways by nurses:

- Ensuring that patients and primary caregivers are provided with information on the care of the patient to make proper decisions and have access to health care services.
- Ensuring that the health care services provided meet the needs of the patient and primary caregiver to ensure that proper care is provided to the patient.
- Obtaining informed consent from the patient and primary caregiver before any procedure is performed and care is provided.
- Ensuring that patients know their rights and have access to care.

**Guideline 2: Nurses should ensure that patients and primary caregivers are empowered to make decisions relating to care by providing adequate information and ensuring privacy and confidentiality.**

**Rationale**

Involving patients and primary caregivers in decision-making is important for achieving quality care. The palliative care clinic/hospital makes patients and primary caregivers aware of their rights and protects them.

**Actions**

This is achieved in the following ways by nurses:

- Ensuring that mechanisms are in place to involve patients, family members and primary caregiver in the care through information sharing.
- Ensuring that patient and primary caregiver beliefs, values and cultural practices are known, documented and respected.
• Ensuring that informed consent is obtained from the patient before involving the primary caregiver and family members where possible.
• Providing an environment where privacy and confidentiality are respected at all times
• Making sure that care is individualized and reflects the preferences and thoughts of the patient.
• Ensuring that the patient and primary caregiver receive sufficient information to assist in making informed decisions.
• Ensuring that the multidisciplinary team is involved in providing the patient and primary caregiver with information on the planned care, alternative care or services to be provided.
• Making sure that the patient gives informed consent for specific procedures and care and this is noted in the patient records and the primary caregiver is made aware of this.
• Ensuring that if someone else gives consent other than the patient, it gets noted and documented in the patient’s records.

Guideline 3: Nurses should ensure that records of patient care and support provided to caregivers are kept confidentially at all times to avoid access to information by unauthorized people affecting confidence in the nurses.
Records of all activities, and patient care should be kept safely and confidentially in accordance with existing health care system policies.

Rationale
Records are legal documents and they assist in ensuring that follow-up care is achieved. They are also used for educational purposes and for the support of the patient.

Actions
This could be achieved by nurses through the following:
• Ensuring that all nurses have knowledge of the policy relating to record keeping and health care facilities provide training on this.
• Ensuring that records are not accessed by unauthorized people.
• Ensuring that a proper filing system is put in place to allow easy identification of records.
• Implementing a system to monitor location and access of records at all times.
6.3.2 RESOURCES MANAGEMENT

The clinic/hospital needs an adequate number of qualified staff members with the relevant experience to meet patient and primary caregiver needs at all times. The clinic/hospital needs to provide sufficient clinical resources to ensure that proper care and support to primary caregivers is provided. Human and clinical resources have been discussed as follows:

6.3.2.1 Provision of human resources for patient care

Guideline 4: Palliative care clinic coordinator/manager in conjunction with nurses should ensure that plans for adequate staffing are tailored with patient needs and ratio, and that a minimum of 2 nurses is allocated in palliative care on daily basis to achieve proper care of patients and support of primary caregivers.

Rationale
Adequate staffing is vital for proper delivery of nursing care. The clinic coordinators or managers work together with departmental nursing managers, nursing management and hospital managers in a collaborative process when planning for proper and adequate staffing based on palliative care knowledge and skills. Ongoing monitoring of planned and actual staffing is updated and other requirements are included as necessary.

Adequate staffing would result in improvements in:

- Quality of care for patients.
- Support of primary caregivers.
- Patient access to palliative care services.
- Knowledge of palliative care nurses through provision of training opportunities and mentorship of staff members.

Actions
This is achieved in the following ways by clinic coordinators/managers and nurses:

- Ensuring that the objectives of the clinic and service provision are taken into consideration when planning for staffing.
• Ensuring that a written plan for staffing is made available at the clinic and hospital level.
• Making sure that palliative care training is considered when planning for staffing to have the right mixture of qualified and experienced staff in palliative care.
• Ensuring that a minimum number of two nurses be allocated in palliative care clinic on daily basis with consideration to mix of patients and services provided.
• Ensuring that provision of locum is made available during planning to ensure adequate number of nurses at all times.
• Ensure availability of a written roster monthly and updated weekly for both nurses and doctors.
• Ensure availability of counselors for nurses to refer patients and primary caregivers to in case there is need of counseling.
• Ensure availability of a Clinical Officer or Doctor on a daily basis for nurses to refer patients who they were unable to handle for proper management.

6.3.2.2 Provision of clinical resources for patient care
Guideline 5: Nurses should ensure that they give adequate and appropriate clinical resources such as gloves, dressings, bandages, cotton wool, gauze, wound cleaning solution and sanitary pads to the patient and primary caregiver for quality care to be achieved

Rationale
The clinic/hospital should have adequate and appropriate resources available at all times for nurses to provide to the primary caregiver and patients to achieve good quality care.

Adequate and appropriate clinical resources would ensure that:
• Quality care is provided to the patient.
• The primary caregiver is supported.
• Infection prevention is achieved by the patient and primary caregiver.

Actions
This is achieved in the following ways:
• The clinics/hospitals ensure that adequate clinical resources are available at all times for nurses to use and provide to patients and primary caregivers.
• Nurses assess the patient and primary caregiver needs for clinical resources and provide sufficient clinical resources at each clinic visit.
• The patient and primary caregiver be supplied with gloves, bandages, cotton wool, gauze and wound cleaning solution and sanitary pads according to the need.
• Nurses demonstrate to the patients and primary caregivers on how to use the provided resources.
• Nurses use a proper ordering system for clinical resources to avoid running out.
• Nurses keeping records of resources ordered, distributed and stored for proper monitoring.
• A designated person is chosen to ensure that resources are ordered in a timely manner, stored and distributed appropriately to primary caregivers according to the need.
• An inventory of stored resources be done quarterly by palliative care nurses, and additional resources ordered to ensure that resources are available at all times.

6.3.3 IMPROVING KNOWLEDGE IN PALLIATIVE CARE

Guideline 6a: Clinic managers and coordinators in collaboration with the nursing and hospital management need to identify learning gaps of staff members and provide opportunities for educational and professional advancement.

Guideline 6b: Effective support of nurses is ensured through provision of mentors, a proper referral system and Continuous Professional Development (CPD) meetings for proper care of patients and support of primary caregivers since knowledgeable nurses would provide proper support and impart knowledge and skills to primary caregivers which would contribute to proper care of patients at home.

Rationale
Properly trained nurses are important in provision of quality care to HIV/AIDS patients and support of primary caregivers through imparting knowledge. The clinic/hospital or organization should support training opportunities that are in keeping with its objectives, needs and resources. The aim of provision of palliative care training, CPD meetings and availability of mentors is to improve knowledge of the nurses which would contribute to proper support of primary caregivers to achieve quality patient care.
Actions
This is achieved in the following ways by nurses and has been discussed further in sub-topics that follow:

- Provision of palliative care training to nurses.
- Arrangement and provision of regular CPD meetings for palliative care nurses.
- Provision and establishment of mentors for palliative care nurses.
- Ensuring that nurses are proactive in imparting knowledge and skills to the patient, family members, primary caregivers and others as necessary

6.3.3.1 Provision of palliative care training

Guideline 7: The clinic coordinators/managers and all nurses involved with palliative care should ensure that they receive palliative care training according to their scope of practice to enable them to provide quality care to patients and support primary caregivers

Benefits of having nurses trained in palliative care:

- Adequate knowledge and skill to provide care to patients and support primary caregivers in palliative care.
- Provision of quality care to patients.
- Ensures safety of care provided to patients

Actions
This is achieved in the following ways by clinic coordinators/managers and nurses:

- The clinic/hospital should have a written plan for staff training in palliative care.
- The clinic coordinators/managers should ensure that palliative care trained nurses are allocated to palliative care clinic and ensure that those not trained in palliative care receive appropriate training within a specified time frame.
- The clinics/hospitals should provide all categories of staff with appropriate training in palliative care.
- Training institutions should incorporate palliative care in the Nursing and Midwifery curriculum to ensure that theoretical and practical training is provided to all nurses before graduation.
• Opportunities for nurses to advance with postgraduate diplomas or degrees in palliative care should be made available by hospital/clinic management.

• Clinics and hospitals should work with stakeholders such as training institutions, nurses and Midwives Council of Malawi and Ministry of Health to ensure that specialization in palliative care is made available in Malawi and reduce costs of travelling to other countries for such qualifications.

6.3.3.2 Provision of CPD meetings for palliative care nurses

Guideline 8: Each nurse working in palliative care should ensure that they attend the scheduled CPD meetings periodically according to the learning needs for quality care to be achieved to patients and support of primary caregivers.

Rationale

For continuous quality care provision to patients and caregivers, CPD meetings are important for nurses. The clinic/hospital management should establish a system whereby the nursing staff members are able to identify and submit their learning needs to the clinic coordinators and managers quarterly. In a collaborative effort the clinic coordinators or managers, departmental nursing managers, nursing management and hospital managers should meet the learning needs of its staff members to achieve the goals of the clinic or organization. Ongoing monitoring of CPD records should be done quarterly to track progress and identify unmet needs to be addressed in the next quarter..

Benefits of CPD:

• Improve knowledge and skills of nurses and quality of patient care.
• Identify knowledge gaps.
• Provision of peer support professionally.
• Offers opportunities for debriefing and sharing experiences.
• Provision of professional growth.
Actions
This is achieved in the following ways:

- The objectives of the clinic and service provision should be taken into consideration when planning for CPD meetings.
- A written plan for CPD meetings should be made available at every clinic and hospital for proper implementation and follow-up.
- CPD committee should be available at each clinic/hospital for smooth running of activities and accountability.
- Learning gaps identified by staff members should be considered when planning for CPD meetings.
- Clinics/hospitals should provide all categories of staff with CPD training according to their needs.
- Departments and nursing management should provide adequate time for staff members to participate in CPD meetings.
- Monthly CPD meetings should be made available at each clinic, hospital and organization based on identified needs.
- The CPD committee should identify proper trainers and equipments for CPD meetings.
- CPD sessions should identify updated information according to research.
- CPD committee members should meet and update each other quarterly on progress.
- Proper records of CPD meetings should be kept for easy tracking of activities and need for improvement.

6.3.3.3 Provision of mentors for palliative care nurses

Guideline 9: Clinics and hospitals should ensure that mentors are available for support and knowledge sharing with newly qualified and less experienced nurses for quality patient care and support of primary caregivers to be achieved

Rationale
For continuous quality care provision to patients and proper support of caregivers, mentors are important in palliative care. The nursing management in collaboration with clinic managers and
coordinators should assign experienced and qualified nurses to mentor and support the less experienced ones. Ongoing monitoring of mentorship process should be recorded and reported.

Benefits of mentorship in palliative care:

- Provides guidance to the inexperienced nurses
- Improves quality of patient care
- Facilitates learning and sharing of experiences
- Assists in acquiring of new skills and increases confidence
- Enhances leadership skills and reduces stress
- Accelerates acclimatization to the culture in palliative care
- Provision of professional growth and cultivates nurse leaders

**Actions**

This is achieved in the following ways:

- Qualified and experienced state registered nurses identified as mentors should be available on daily basis for proper professional and psychological support of nurses.
- Nurses who attended one to two weeks training in Malawi should be mentored by qualified state registered nurses until proper experience and skill is achieved.
- The period for mentoring nurses should be stipulated and need for more time documented accordingly.
- Nurses should identify gaps during mentorship process and be assisted accordingly.
- Mentorship programme committee members should meet and update each other quarterly for progress.
- Proper records of mentorship programme and meetings should be kept and shared with management for improvement of activities.

6.3.3.4 Imparting knowledge and skills to the patient, family members and primary caregivers

**Guideline 10:** Nurses should ensure that they impart necessary knowledge and skills to the patient, family members and primary caregiver for continuity of care and to improve quality of care to the patient
Rationale
Continuity of palliative care for HIV/AIDS patients is achieved with health education of the patient, family members and primary caregivers since these patients are nursed at home. This education empowers them to participate in the care at home and assists them in decision making. Nurses can achieve this by proper education, planning, delivery and recording of health information. During education delivery, nurses needs to take into account the age, educational level and beliefs of the patient and caregiver, and also the condition of the patient, family members and primary caregiver.

Actions
This education could be achieved in the following way:

- Nurses provide instruction to patients and primary caregivers on their respective roles and expectation with activities of daily living such as assistance with bathing, feeding, elimination, washing and home hygiene.
- Nurses should teach the family and primary caregiver on the patient’s condition, treatment that the patient is getting, opportunistic infections such as kaposi’s sarcoma, prevention of parent-to-child HIV transmission and any condition that can arise as a result of HIV infection.
- Nurses should demonstrate to the primary caregiver the skill of providing physical care to the patient, such as assistance with bathing, eating, mobility, changing positions in bed, elimination of both stool and urine and wound care as necessary.
- Nurses should teach the patient and primary caregiver on the treatment that the patient is getting and importance of adherence such as ART, antibiotics and analgesics.
- Nurses should teach the patient and primary caregiver on the side effects of the medication and what to do if that happens.
- Nurses should teach the primary caregivers on how to prevent contracting HIV while caring for patients by using gloves and general infection prevention measures such as washing hands after assisting the patient, soaking clothes and beddings soiled with body fluids in hot water and Jik or chlorine before washing especially when gloves are scarce.
• Nurses should teach the primary caregivers and patient on prevention of parent to child transmission of HIV as follows:
  o Education on feeding of the baby using option B+ for HIV positive women where babies are exclusively breastfed for the first six months before introducing other foods as per HIV policy
  o Availability of services for the mother and the HIV exposed child and also prophylactic treatment if necessary
  o Importance of adherence to ART
• Nurses should teach the patient and primary caregiver the different cancers that are common in Malawi such as cancer of the cervix, and include the following information:
  o The cause and those at risk
  o Signs and symptoms
  o Screening tests available such as Visual inspection using Acetic acid (VIA) for cervical cancer for early diagnosis and treatment
  o The available treatment and preventive measures
• Nurses should teach the primary caregivers, patient and community members on preventing infections in sero-discordant and sero-concordant relationship by using condoms at all times when having sexual intercourse if applicable
• Nurses should inform patients and primary caregivers of Community Based Organizations (CBO) and other organization that deal with chronic conditions in their community and should link the patient and primary caregiver with them as necessary.

6.3.4 HOLISTIC APPROACH IN PALLIATIVE CARE

Guideline 11: The nurses should assess and manage the patient holistically which includes the physical, psychosocial and spiritual aspects, be able to involve the multidisciplinary team and coordinate the care provided but also communicate findings to the primary caregiver and teach them to observe any deviations at home and report to the nurses.

Rationale
Providing holistic care to patients is the only way of meeting all the needs of patients but needs proper assessment of patients, planning and coordination of services since each patient is unique.
Palliative care nurses need to assess and manage the patient needs holistically and teach primary caregivers the skill of providing holistic care to patients since they are nursed by them at home which should incorporate physical, psychosocial and spiritual aspects which could influence responses to an illness. The nurses, clinic managers, coordinators and hospital management need to look at ways of achieving holistic patient care in conjunction with the primary caregivers by providing tailored health care services, proper referral systems and multidisciplinary care team approach.

The multidisciplinary team could consists of the following members: nurses, medical doctors, pastors or spiritual leaders, social workers, dieticians, physiotherapists, occupational therapist, counselors, primary caregiver, psychologists and others if necessary. The nurse ensures that multidisciplinary team meets the physical, psychosocial and spiritual needs of the patient by involving the primary caregiver in a coordinated manner.

Benefits of holistic assessment of patients:

- Patient needs are identified
- Proper planning on management is achieved
- Quality holistic patient care is achieved
- The need to involve multidisciplinary team is identified
- Assists in giving an insight on prognosis of the patient
- Proper referrals are made to the appropriate team members
- Empowerment of the primary caregiver and the family is achieved
- Family centered care is achieved

**Actions**

This is achieved in the following ways by nurses:

- Palliative care nurses should perform a physical, social, spiritual and psychosocial assessment on a patient and abnormalities that could be found should be communicated to the primary caregivers in simple layman terms during clinic visits.
• Palliative care nurses should communicate the initial findings to primary caregivers and use the findings as reference to subsequent ones throughout the care process to evaluate patients progress
• Palliative care nurses should assess patients pain using pain scores and ensure that primary caregivers are taught on how to monitor pain and that assessment of distressing symptoms is included at all times
• Palliative care nurses should assess the patients activities of daily living and teach primary caregivers to observe any deterioration for better planning on type of care to be provided
• The palliative care nurses should also teach primary caregivers to report deterioration and improvement of the patient’s condition to the nurses during clinic visits for proper plan of care.

6.3.4.1 Physical aspects of care
Guideline 12: The nurse should ensure that physical assessment and management of the patient is conducted on each visit and teaches the primary caregiver on physical care to provide at home and assess the need to involve the multidisciplinary team in a coordinated manner.

Rationale
The provision of physical palliative care is achieved by the nurse, primary caregiver and the multidisciplinary team coordinated by the nurse by effective assessment of the patient which would ensure that adequate care is provided and teaching the primary caregiver on care provision at home.

Actions
This is achieved in the following ways by the nurse:
• The palliative care nurse should conduct pain assessment on the patient using pain assessment scales and pain management using WHO analgesic ladder on each contact with the patient and teach the primary caregiver in simple terms on regular monitoring and management of pain at home
• The palliative care nurse should assess and manage distressing symptoms that a patient could have and teach the primary caregiver on managing the symptoms at home
• The palliative care nurse should assess the activities of daily living of the patient and type of care required and teach the primary caregivers on this assessment and the need to communicate to the nurse on deterioration (such activities of daily living could include assistance with bathing, feeding, elimination, washing, position changing in bed, wound care and home hygiene). The need for assistance with these activities should be communicated and proper assistance provided
• The palliative care nurse should involve a doctor or clinical officer, dietician, physiotherapist, primary caregiver and family members in physical care of the patient according to the need and assessment
• The palliative care nurse should teach the primary caregiver on physical care of the patient according to the need
• The primary caregiver should be taught to communicate her management of pain and other symptoms and all the physical aspects of care performed to the patient at each visit and roles taken by different members. The palliative care nurse should document and assess need for more support on physical care as needed.

6.3.4.2 Psychosocial aspects of care

Guideline 13: The nurses should ensure that psychosocial aspects of the patient and primary caregiver are assessed and managed which should include teaching the primary caregiver the management of psychosocial aspects of the patient and need to involve the multidisciplinary team in a coordinated manner.

Actions
This is achieved in the following ways by the nurse:
• Assessing the cultural beliefs that affect care provided and education to the patient and also teaching the primary caregivers on this
• Assessing emotional issues affecting the patient and provide support and teaching the primary caregivers provision of psychosocial support
• Involving different multidisciplinary team members such as doctors, nurses, social workers, psychologists and primary caregivers in psychosocial care of the patient as needed
• Educating the patient and primary caregiver about the available social support system in the clinic/hospital and community
• Establishing from primary caregivers the need for money for transport to the hospital, money for paying hospital bills for private owned facilities and this should be communicated and proper referrals made to organization/departments as needed
• Documentation of psychosocial aspects of care provided by the primary caregiver and nurse at each visit should be done

6.3.4.3 Spiritual aspects of palliative care

Guideline 14: Palliative care nurses should ensure that spiritual aspects of the patient and primary caregiver are assessed and addressed and need to involve the multidisciplinary team in a coordinated manner.

Actions

This is achieved in the following ways by the nurse:

• Assessing the spiritual needs and beliefs of the patient and primary caregiver which could affect the health of the patient and provide spiritual counselling
• Ensuring that primary caregivers identify the spiritual leaders for the patient and have the contact details in case the need arises
• Educating and supporting the primary caregiver on identified spiritual needs of the patient
• Identifying the need of involving different multidisciplinary members such as doctors, nurses, spiritual leaders and primary caregivers in spiritual care of HIV/AIDS patients
• Provision of bereavement support to the primary caregiver and family in case of death and how to carry on for example for the living spouse
• Teaching primary caregivers to communicate the spiritual support provided to the patient and documentation in the patient records should be done and referrals made as necessary on each visit
6.3.4.4 Nutritional aspects of palliative care

Guideline 15: Palliative care nurses should ensure that primary caregivers are aware of nutritional needs of the patient and address this through nutritional assessment and need to involve the multidisciplinary team is coordinated by the nurse.

Actions

This is achieved in the following ways by the nurse:

Palliative care nurses should teach primary caregivers on nutritional assessments of the patient such as observing appetite and food habits. The palliative care nurse should conduct the following nutritional assessment when the patient comes to the clinic:

- Use of health passport for adults to check and compare the patients weight at each visit
- Use of anthropometric methods to measure body height and weight, mid upper arm circumference for children and head circumference
- Calculate Body Mass Index (BMI) using the following formula: BMI = Weight (kg)/Height (m²)
- Interpret BMI according to WHO (2011: 20) guide for proper advice and management as indicated in table 6.3 as follows:

<table>
<thead>
<tr>
<th>BMI</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 18.0</td>
<td>Under Weight</td>
</tr>
<tr>
<td>18.5-24.9</td>
<td>Healthy weight range</td>
</tr>
<tr>
<td>25-29</td>
<td>Overweight (grade 1 obesity)</td>
</tr>
<tr>
<td>&gt;30.0 – 39.9</td>
<td>Grade 2 obesity)</td>
</tr>
<tr>
<td>&gt;40</td>
<td>Very obese (grade 3 obesity)</td>
</tr>
</tbody>
</table>

- The palliative care nurse should document her findings and initiate the plan of care or refer to multidisciplinary members such as dietician
- The palliative care nurse should ensure that the dietician is involved in nutritional care of the patient according to the need
The palliative care nurse should consider the patient’s and primary caregiver’s beliefs, food habits and preferences when teaching the primary caregiver about nutritional needs of the patient.

The palliative care nurse should calculate the BMI of the patient at each visit and recommended type and intake of food at each visit communicated to the primary caregiver.

The palliative care nurse should educate the patient and primary caregiver on nutritional requirements of the patient using the six food matrix while considering Malawian locally available foods as follows:

- Group 1: food from animals for example eggs, fish, usipa
- Group 2: food from legumes for example beans, soya beans, khobwe
- Group 3: food from fats for example avocado pears, cooking oil
- Group 4: food from vegetables for example chisoso, pumpkin leaves
- Group 5: food from cereals/staples for example rice, sorghum, maize, cassava and potatoes
- Group 6: food from fruits for example bananas, mangoes, guavas, zipwete and paw-paws

The patient and primary caregiver should be educated on proper preparation and storage of food by the palliative care nurse.

Based on nutritional assessment, palliative care nurses should provide nutritional supplements such as ready to use therapeutic feeds such as plumby nuts according to the government policy and monitor improvement or deterioration of the patients nutritional status on each clinic visit but also communicate this to the primary caregiver.

Palliative care nurses should assess the need and be able to involve different multidisciplinary members such as doctors, nurses, dieticians in nutritional assessment and management of patients and communicate this to the primary caregiver.

Palliative care nurses should assess the primary caregivers source of income and encourage involvement in income generating activities such as gardening so that they meet nutritional needs of the patient.
• Palliative care nurses should assess other sources of financial support for the primary caregivers such as family members and need for further support be known to social welfare department as needed so that patients nutritional needs are met
• Palliative care nurses should document the nutritional report provided by the primary caregiver, and nutritional care provided but also education and supplements provided at each visit

6.3.4.5 Effective Medication Management

Guideline 16: Nurses should ensure that proper ordering, storage, dispensing, prescribing, administering, monitoring and record keeping of medications is achieved in a collaborative process between nurses, doctors, pharmacy and administrative staff for effective palliative care provision to the patient and proper support of the primary caregiver.

Rationale

The provision of quality palliative care is achieved by effective medication management. Medications are an important resource in patient palliative care. The clinic/hospital ensures that appropriate medications are available at all times to meet the needs of the patients especially analgesics.

Actions

Effective medication management is achieved by palliative care nurses in the following ways:

• Palliative care nurses should ensure that an appropriate selection of medications is readily available to meet the needs of the patients using a drug list and in consultation with doctors and clinical officers. These medicines should include the following: cotrimoxazole, amoxicillin, aspirin, Ibuprofen, paracetamol, morphine sulphate and codeine phosphate, ART and other medications as necessary
• Ensuring that the drug ordering process is clear and the person responsible be clearly stipulated
• Have a documented drug control system available and followed at all times
• Expired drugs should be disposed appropriately or donated according to the policy
• Medications should be stored in a clean store room with lockable cupboards
• Controlled substances should be stored in a lockable cabinet and proper records of ordering and dispensing should be followed
• Medications should be stored according to manufacturers guidelines as necessary
• Drugs should be weekly checked for expiry dates and correctly labeled
• A refrigerator should be made available for medications requiring low temperatures as necessary
• Only doctors, clinical officers and trained palliative care nurses should prescribe and dispense medications in palliative care clinics
• The response to medications should be monitored and evaluated so that dose adjustments are done accordingly and efficacy is monitored
• Effects and adverse effects to medications should be communicated to both the patient and primary care giver and actions taken accordingly and side effects should be documented in the patient records
• The patient and primary caregiver should be made aware of the side effects associated with different drugs such as constipation for morphine sulphate and preventive measures should be implemented
• Medication errors should be documented and staff should be trained to prevent these
• CPD training should include medication management
• The patient and primary caregivers involved in medication administration should be educated as an on-going process on the name, reason, times of medication administration, side effects and what to do if the patient develops side effects and should also be provided with written instructions
• There should be a collaborated documented drug control system by each member involved to ensure safety of the patient

6.3.4.6 Pain Management Using WHO Analgesic Ladder
Guideline 17: Nurses should ensure that they have taught primary caregivers on how to assess pain in a patient using different scales and how to use the WHO analgesic ladder to control pain
Rationale
The provision of quality palliative care is also achieved by effective pain management since palliative care patients are mostly in physical pain. As such physical pain assessment should be taught to primary caregivers in simple terms using proper scales as shown in the figure 6.3 below and pain is managed accordingly using the WHO analgesic ladder.

![Pain Score 0-10 Numerical Rating](image)

![Wong Baker Face Scale](image)

Adapted from Hocenberry M.J.: Wong’s Essentials of pediatric Nursing (2005)

**Figure 6.3: Pain assessment scales**

Actions
Effective pain management is achieved by the following:

- Palliative care nurses should teach primary caregivers on how to conduct a proper assessment of patients pain accordingly using a proper scale
- Primary caregivers should be taught on how to classify patients pain accordingly whether the patient is having mild, moderate or severe pain
• Nurses should teach primary caregivers on analgesics to be given to the patients according to pain scale on assessment and WHO analgesic ladder (Vargas-Schaffer, 2010) as shown in the figure 6.4 below

• Nurses should teach primary caregivers on how to monitor effect of analgesics on the patients pain and move to the next step of analgesic ladder if need be

• Nurses should teach primary caregivers on how to manage patients pain at home and advice them to come to the clinic/hospital or phone the clinic if pain control fails.

• Nurses should teach the primary caregiver on documentation of pain management given to the patients

![WHO Analgesic Ladder](image)

Figure 6.4: WHO analgesic ladder

6.3.4.7 One-stop Clinic for Health Care Services

Guideline 18: Nurses should ensure that each patient and primary caregiver have access to tailored health care services based on the identified health care needs using one-stop clinic services

**Rationale**

In order to provide proper care to HIV/AIDS patients and support of primary caregivers, the clinics/hospitals providing palliative care ensures that health care services are tailored to meet all
the needs of patients. This is achieved by the multidisciplinary health care team through proper communication channels and referral system.

Benefits of providing tailored health care services for patients:
- Continuity of care is achieved
- Proper planning of care is addressed
- Support of primary caregivers is achieved
- Care provided is coordinated
- Saves time and money

**Actions**

**Provision of one-stop clinic**
- The clinic/hospital should provide one-stop clinic services where patients have access to all health care services needed such as family planning, palliative care services, ART provision, antenatal clinic, under-five clinic, treatment of infectious diseases and support services for primary caregivers based on the needs
- The one-stop clinic service should ensure that HIV/AIDS patients and primary caregivers are attended to and treated promptly by nurses without being stigmatized
- Health care appointments should be scheduled in a flexible way so that both the patient and primary caregiver are available on appointment days as required
- Nurses should ensure that the care provided to the patient and the type of support to the primary caregiver is documented for continuity of care to be achieved.
- Involvement of other members of the multidisciplinary team should be identified and proper referrals made and documented.

6.3.4.8 **Provision of Proper Referral System**

**Guideline 19:** Nurses should refer patients with conditions outside their scope for further management and proper referral link should be used when referring patients between health centres, district hospitals and central hospitals.
**Rationale**

In order to provide proper care to HIV/AIDS patients and support of primary caregivers, the clinics/hospitals providing palliative care ensures that proper referral systems are in place for both the patient and primary caregiver.

**Actions**

This is achieved in the following ways by nurses:

- A proper referral system for both the patient and family caregiver should be available at each clinic/hospital and health care setting
- Nurses should have a list of palliative care service providers in different clinics and a list of palliative care clinics in Malawi for proper referral of patients to be achieved
- A documented referral system should be available for nurses at health centres, district hospital and central hospitals for cases that they fail to handle.
- A proper referral link and contact details should be available for nurses between the health centres, district hospitals and central hospitals to achieve proper follow-up of patients.

**6.3.4.9 Continuity of Patient Care**

**Guideline 20:** Nurses should ensure that continuity of patient care at home is achieved through involvement of primary caregivers, visitations and communication

**Rationale**

Continuity of palliative care is achieved when nurses know what is happening in the patients homes and this calls for them to visit the primary caregivers at home and be in touch with them to ensure continuity of care. The clinic/hospital plans, coordinates and schedules for home visitations of the patient and primary caregiver to achieve this continuity and ensures that transport is provided for this process. It also ensures that the patient is in contact with the nurses at all times.

**Actions**

Visitations could incorporate the following:
• Nurses should plan their visitations in such a way that there is availability of both the patient and primary caregiver so that it is meaningful.

During visitations nurses should:

• Provide supervision to the patient and primary care giver on the care provided during visitation
• Teach primary caregivers on specific needs of the patients
• Assist in resource provisions
• Ensure that primary caregivers are taught on infection prevention, psychosocial counselling and nutrition
• Assist in establishing support structures at a family and community level as the primary caregiver takes on their new role
• Assess the need for respite support of the primary caregiver and suggest options such as family members, volunteers, community members and church members
• Assist the patient to have continued care in case of primary caregiver incapacitation and respite care for primary caregiver as needed
• Involve the primary caregivers in the care during clinic visit
• Assess the need for support from family members, community and church members and suggest ways of involving these members in different roles such as assistance with physical care and financial support.

6.3.4.10 Communication

Guideline 21: Nurses should ensure that proper communication channel exist between them and primary caregivers to ensure adequate support of primary caregivers and achieve continuity of care

Rationale

Support of primary caregivers and continuity of patient care is achieved through the proper communication between palliative care nurses and primary caregivers.

Actions

Communication should include the following:
• Nurses should devise a mechanism through which patients and primary caregivers can contact them.
• Nurses should provide the patient and primary caregiver with telephonic contacts of the clinic and palliative care nurses for communication if they need advice on the patients
• Constant communication should exist between nurses, patients and primary caregivers at all times
• Nurses should involve the primary caregivers in the care during clinic visits so that they know their role at home
• When the patient is admitted in the hospital nurses should ensure that they share knowledge to the patient and primary caregivers for continuity of care at home

6.3.5 MONITORING, EVALUATION AND REPORTING

Guideline 22: Palliative care nurses should ensure that proper monitoring and evaluation of services exist to inform decision making.

Rationale
Palliative care nurses should have proper records and execute monitoring and evaluation of services. This process should be put in place to ensure that decision making is informed by evidence.

Benefits of monitoring and evaluation
• Evidence based practice is achieved
• Decision making is effectively informed
• Progress of the services and their effects are tracked
• Patient needs and safety is achieved
• Patient care is supported

Actions
Details of monitoring, evaluation and reporting are as follows:
• Nurses should ensure that management have put in place plans describing how monitoring, evaluating and reporting will take place and people responsible for
monitoring, evaluating, record keeping and reporting of palliative care services including support of primary caregivers

- The monitoring and evaluation plan for each health facility should be clear and include a budget for implementation of the whole process
- Clear indicators should be identified to assist the monitoring and evaluation process
- The monitoring and evaluation team should be available at each health facility and should have clearly stipulated roles and activities.
- Monthly reports should be generated and quarterly monitoring and evaluation should be done to inform decision making
- Monitoring and evaluation forms should be developed to assist in this process

6.4 TRUSTWORTHINESS OF THE GUIDELINES
Trustworthiness ensures that the guidelines are credible and reliable which was achieved by input of the experts on the guidelines and the process followed. In addition, the use of three consultation rounds on the guidelines led to consensus on the issue under discussion and refined the guidelines. Furthermore, the experts were provided with the description of their expectations in the covering letters which accompanied the guidelines requesting for their comments on the draft of guideline statements, additional information and changes that were necessary. The allocation of a period of 1 - 2 weeks for experts to make comments although they took a longer period to respond also ensured trustworthiness of the guidelines. The final guidelines were also presented to the experts for evaluation and six of them evaluated the guidelines using an appraisal tool and reached a consensus.

6.5 APPRAISAL OF GUIDELINES FOR RESEARCH AND EVALUATION (AGREE)
The Evidence-Based Guidelines Development (EBGD) (2006: 30) process state that guidelines should be credible and reliable using the six domains of the Appraisal of Guidelines for Research and Evaluation (AGREE) for quality of practice. The developed guidelines were evaluated using critical reflection and six domains of AGREE. The critical reflection guide checked for clarity, simplicity, generality, accessibility and importance of the guidelines (Chinn & Kramer, 2008: 246 – 248). The AGREE domains checked for the scope and purpose of the guidelines,
stakeholder involvement, rigour, clarity and presentation, applicability and editorial independence. The evaluation domains are presented in table 6.3 and were applied as follows:

**TABLE 6.3: SIX DOMAINS AND APPLICATION OF GUIDELINES FOR QUALITY PRACTICE AND CRITICAL REFLECTION**

<table>
<thead>
<tr>
<th>Domain</th>
<th>How it was applied</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scope and purpose</strong></td>
<td>The objective of the guidelines has been specifically described. The clinical question covered by the guideline was specifically described. The patients to whom the guidelines are meant to apply are specifically described.</td>
</tr>
<tr>
<td><strong>Stakeholder involvement</strong></td>
<td>Patients’ views and preferences were sought and the target users of the guideline are clearly defined. Guidelines were based on data obtained from HIV/AIDS patients, primary caregivers and palliative care nurses. Experts in HIV/AIDS, palliative care and all the relevant professional groups contributed to the development of the guidelines</td>
</tr>
<tr>
<td><strong>Rigour</strong></td>
<td>Data were collected from HIV/AIDS patients, primary caregivers and palliative care nurses. An integrative review was conducted to gather evidence supporting the guidelines where an explicit link exists. The guidelines were reviewed by experts</td>
</tr>
<tr>
<td><strong>Clarity, simplicity and presentation</strong></td>
<td>The language used is simple and the format is easy to follow and unambiguous. The key areas are easily identifiable and the different options for management of the specific situations are clearly presented.</td>
</tr>
<tr>
<td><strong>Applicability and importance of guidelines</strong></td>
<td>The guidelines are based on research findings from the target population of primary caregivers, HIV/AIDS patients and palliative care nurses and are important for quality patient care and better quality of life for HIV/AIDS patients</td>
</tr>
<tr>
<td><strong>Accessibility of the guidelines</strong></td>
<td>The guidelines to be placed at a place where they are accessible by all users</td>
</tr>
<tr>
<td><strong>Editorial independence</strong></td>
<td>This was achieved by the use of experts</td>
</tr>
</tbody>
</table>

**6.6 SUMMARY**

This chapter has discussed the developed guidelines and the process that was followed. The guidelines have been developed for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. The EBGD process and NICE process that was followed has been presented and the experts who assisted in refining the guidelines are also discussed. The following chapter discusses the conclusion, limitations and recommendations of the study.
CHAPTER SEVEN

SUMMARY, CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

7.1 INTRODUCTION

The previous chapter discussed the guidelines that have been developed to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. This chapter concludes the study on developing guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi that was outlined in the preceding six chapters. This research study was conducted in three phases and has been presented in seven chapters. In a nutshell, this chapter highlights some of the central issues raised in the study. Therefore, it is organized according to the layout of the individual chapters of the thesis.

Phase one of the study has been presented in chapters one to four; phase two has been presented in chapter five and phase three has been presented in chapters six and seven. The first chapter provided the background of the study, which included among others the problem statement, research purpose, objectives of the study, motivation and significance of the study. Chapter two discussed the methodology of the study, which included two sections. The first section examined the qualitative paradigm with explorative, descriptive and contextual design which has been used in this study and its underpinnings and justification. The second section includes the data collection process, sampling and collection methods, data analysis, trustworthiness and ethical consideration. Chapter three presented the research findings from three groups of participants namely: palliative care nurses, primary caregivers and HIV/AIDS patients where their needs were revealed.

Chapter four discussed the key findings of the study from palliative care nurses, HIV/AIDS patients and primary caregivers in relation to literature. The discussion showed that the needs from the three groups of participants from the study were similar to findings from literature. It also discussed support as a need from the three groups of participants. Since the study aimed at developing guidelines for nurses to support primary caregivers of HIV/AIDS patients chapter five synthesized existing evidence regarding support to primary caregivers in palliative care in an
integrated literature review for better understanding of the concept. The integrated literature review described support to caregivers in palliative care as the most important strategy for improving care of patients and improving the quality of caregiver lives which would ensure that the caregiver needs are met and have a positive impact on caring. Chapter six discussed the guidelines for nurses to support primary caregivers and the process that was followed during the development. The aim of this chapter is to discuss the conclusion, limitations and recommendations drawn from the study.

7.2 SUMMARY OF THE STUDY
The aim of the study was to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care relevant to the local Malawian context. The study used a qualitative, explorative and descriptive design which was contextual in nature and the appropriateness of this approach in this study was discussed. The qualitative research approach was used to describe and understand support of primary caregivers from the participants’ point of view and at the site where participants experienced the issue (Fouche & Delport in De Vos, Strydom, Fouche & Delport, 2011:64-65). Descriptive design assisted the researcher to describe the phenomena accurately with deeper meaning of the situation. Furthermore, an explorative approach assisted the researcher to clarify relationships and identify why certain events occur.

In phase one the objectives were met by conducting in-depth individual interviews with primary caregivers which aimed at exploring and describing their needs in relation to care given to HIV/AIDS patients. In addition, objectives were met by conducting individual in-depth interviews with HIV/AIDS patients to explore and describe their needs in relation to care received from primary caregivers. Furthermore, focus group discussions were conducted with palliative care nurses to explore and describe their needs in relation to supporting primary caregivers of HIV/AIDS patients. The findings from palliative care nurses indicated needs for training, resources, support and guidelines to perform their roles better. The primary caregivers revealed needs for training in their role, resources and need for support and the HIV/AIDS patients indicated their needs as physical care, quality health care services, knowledge, resources and support.
The findings from the three groups of participants showed the need for support to primary caregivers. The objective of phase two was met by conducting an integrative literature review which synthesized existing evidence regarding support to primary caregivers in palliative care. The findings from the integrative literature review proved the importance of supporting caregivers as a strategy for improving quality of patient lives. Furthermore, support of caregivers ensures that their needs are met, reduces high degree of stress and improves their quality of life (Feng, et al., 2009:488). The integrative literature review highlighted that the caregiver role which is normally undertaken by family members and friends generates mental, physical, social and financial stress since caregivers assume multiple roles without preparation and training. The integrative literature review also showed that caregivers need information and education, assistance with personal, nursing and medical care of the patients, resources, financial security and respite support (Payne, et al., 2010:242). The integrative literature review also indicated that caregivers should be provided with training in their role by health care professionals to perform their roles better. As such guidelines for nurses to support primary caregivers of HIV/AIDS patients were developed, described and evaluated meeting the objectives of phase three in this study.

The guidelines development utilised four steps of the modified, adapted and integrated Evidence-Based Guidelines Development process which was conducted in four steps. In the first step of the process thirteen experts were selected based on their work experience in palliative care, HIV/AIDS care, guidelines development and policy making. Furthermore, baseline data was reviewed from study results and the integrative literature review which revealed the need for support guidelines and aspects to be included were identified. These aspects were as follows: need for knowledge of nurses, patients and primary caregivers; quality health care services to HIV/AIDS patients; provision of resources to nurses and primary caregivers for achievement of quality care; provision of support to primary caregivers and monitoring and evaluation of care.

In the second step the current goal was explored which was to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients to achieve proper care of patients and a better quality of life. This was followed by the question which guided the development of the guidelines. This question was as follows: “What are the guidelines for nurses to support primary
caregivers of HIV/AIDS patients in palliative care?” This was followed by the third step in which writing of a consultation draft was done and distributed to experts for their input. After the input from experts, the researcher reviewed the comments and incorporated them in the guidelines and wrote the final draft which was distributed to experts again. The fourth step involved reviewing of comments from experts then writing and submitting the final guidelines to experts for final approval. This was followed by appraising the guidelines by six experts using an appraisal tool then the final guidelines presented in chapter six were written. The final guidelines covered five areas as follows: ethics and caring, resource management, holistic approach in palliative care, improving knowledge in palliative care, record keeping, monitoring, evaluation and reporting.

7.3 RECOMMENDATIONS
Recommendations have been proposed for the successful use of the guidelines. The recommendations discussed include the ones for the nurses, primary caregivers, HIV/AIDS patients, nursing practice, nursing education and research.

Recommendations for palliative care nurses
Skills for palliative care nurses

- Palliative care nurses should commit themselves and adapt to a family-centred approach to achieve holistic care of the HIV/AIDS patients.
- All palliative care nurses should be provided with training sessions designed to prepare them for care provision to the patients and support of primary caregiver in all areas
- Different training strategies should be used to train palliative care nurses in preparation and support of their role. The following examples of strategies could be used: mentorship by an experienced registered nurse, workshop session at specific intervals, exchange visits to health facilities that are doing better than them
- Peer support from fellow nurses as an on-going process. In this process palliative care nurses share experiences and support each other such as debriefing sessions. This process could also include nurses who work in non-palliative care departments
- Novice palliative care nurses should be supported in an orientation programme to ensure effective performance and be allocated a mentor for guidance.
- Nurses should ensure that they improve their skills by use of peer assessment, and obtain patient and family feedback on care outcomes
- Nurses should ensure that their training prepares them for diversity in care and include care of other cultures and beliefs which are different from their own and involving stakeholders in the support and care
- Appraisals should be made available for nurses to ensure support, improvement and offer encouragement for better quality of care
- Programs for further development should be available in Malawian nursing schools such as diploma in palliative care and degree programmes to allow nurses to specialize in palliative care if interested.

**Support for nurses**

It is important for nurses to be supported in this role through open communication, sharing experiences and reflection.

- Management should ensure that open communication between them and nurses is achieved and encouraged
- Mentorship should be available for nurses and provided by an experienced person in all the centres
- Nursing support groups should be formed for debriefing and reflective sessions for sharing of situations and effective strategies
- Nurses should be introduced to activities such as team building to ensure that support is achieved.

**Recommendations for primary caregivers**

- Primary caregivers should be provided with information and be trained on caring for their patients. This knowledge will assist in alleviating anxiety and prepare caregivers for their role.
- The primary caregivers should be involved in patient care at the hospital for continuity of care to be achieved when at their homes.
• Training workshops should be introduced for the caregiver and sufficient orientation should be made available for the primary caregiver
• Primary caregivers should be visited at home by nurses at different intervals throughout the year for training and support
• Support groups for primary caregivers and provision of nurses contacts should be provided in an organized way for support provision
• A needs assessment should be conducted on each primary caregiver for provision of proper support
• Primary caregivers should be known and be in contact with palliative care nurses for achievement of proper care

Recommendations for HIV/AIDS patients

• HIV/AIDS patients should be provided with nursing support according to the condition
• A needs assessment should be conducted on each patient for proper care and support
• HIV/AIDS patients should be encouraged to join support groups close to their homes to prevent frustrations about the condition, share experiences and support each other
• HIV/AIDS patients should be given nurses contact numbers for support at home

Recommendations for further research

• Follow-up research should be conducted to evaluate the guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi and its impact in practice.
• Psychological support of the primary caregiver should be given attention especially when dealing with loss of the patient.
• Support provision should be assisted by first doing needs assessment of patients and primary caregivers so that complex relationship is established between primary caregivers’ nurses and patients.
• Guidelines general usefulness might aid in supporting all nurses, and assist nurses to support care givers of patients with other conditions without singling out HIV.
• Future researchers may want to consider use of a theoretical framework when conducting similar research.
• Future research may also want to have a sample of more males than females.

**Recommendations for nursing education**

• The guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care should be introduced in the education of nurses

• The nurses graduating from nursing colleges should be knowledgeable about needs of primary care givers and support interventions for the quality of life of HIV/AIDS patients

• The nursing curriculum should include palliative care in its curriculum at all training levels and include the complex interrelation between support of primary caregivers and palliative care nurses achieving quality care of patients. The development and support strategies should be contained in the curriculum

• The education and training of nurses should be based on supportive approaches and be family-centered

• The guidelines should be presented at an in-service training before being implemented at the palliative care clinics.

**Recommendations for nursing practice**

Findings of the study highlighted the need for nurses to support primary caregivers of HIV/AIDS patients as such the following recommendations have been made:

• In clinical practice, the guidelines for nurses to support primary caregivers of HIV/AIDS patients could be included in the clinical setting of the outpatient department, general admission wards and home based care setting. Other nurses may want to consider transferring this to their practice

• A holistic care achievement of HIV/AIDS patients requires multi-professional and multidisciplinary practitioners and involving all stakeholders

• A needs assessment should be included in the standard care of HIV/AIDS patients in order to provide appropriate care, support and refer appropriately.

• Similar research could be conducted in different districts in Malawi using the same methodology to enable the results to be generalized.
7.4 LIMITATIONS OF THE STUDY
The study had some limitations; it was conducted at three palliative care clinics in Salima and Lilongwe districts of Malawi. Therefore, it could be argued that the selection of participants is not a representation of all the palliative care nurses, primary caregivers and HIV/AIDS patients in all the districts of Malawi. The primary care givers who participated in the study had only two males against fourteen females which could yield different results. Application of the findings to populations with different characteristics should be applied with caution since other gender populations may exhibit unique features which could be barriers to expected outcomes.

In addition, the researcher could not find sufficient literature on support particularly for nurses. Furthermore, other types of support to primary care givers were not considered such as for acute and other chronic conditions such as diabetes and cancer. It is possible that support to primary care givers of patients with other conditions would elicit different themes and inform development of different guidelines.

The final guidelines were presented to only six evaluators due to the busy work demands of the other seven who were included in the process in the initial phases using an appraisal tool (see appendix T for the evaluation guide used). The six evaluators who evaluated the guidelines reached consensus and were satisfied with the development of the guidelines.

7.5 CONCLUSION OF THE STUDY
The purpose of the study was to develop guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi. The study findings verify that HIV/AIDS patients, palliative care nurses and primary caregivers had different needs. It is therefore vital that primary caregivers be supported by nurses for proper care to be provided to HIV/AIDS patients. Guidelines for nurses to support primary caregivers of HIV/AIDS patients have been developed. Recommendations for HIV/AIDS patients, palliative care nurses and primary caregivers have been highlighted including recommendations to nursing education, clinical practice and research. Limitations of the study have also been described. Future work could include evaluation of the impact of the guidelines and validation thereof.
8. REFERENCE LIST


response to the HIV pandemic for two urban slum communities in Pune, India. *PloS One*, 7(9) e44989.


Ministry of Health (2005a) Draft National Policy on Community Home Based Care


APPENDIX A: MAP OF MALAWI FOR THE STUDY SETTING
Appendix B: Ethical Clearance certificates
Appendix C: Institutional endorsement certificate

INSTITUTIONAL ENDORSEMENT REQUIRED

Statement from the Institution:
The NHSRC will only accept for review and approval research proposals that have been found scientifically acceptable by our institution. The acceptable Institutional endorsement will be that from the Institution in which the research is to be conducted or one from the institution conducting the research.

We, representing

UNIVERSITY OF LIMPOPO (MEUNSA CAMPUS)
(Name of Institution conducting the research/in which the research is to be conducted)

do certify that we have reviewed the research proposal titled

Guidelines for Nurses to Support Primary Caregivers of People living with HIV/AIDS (PLWHA) in Palliative Care in Malawi

Submitted by

MRS. TO. MKWINDA

We attest to the scientific merit of this study and the competency of the investigator(s) to conduct the project and do hereby recommend the proposal to the NHSRC for review and approval.

SIGNATURES

Date 01.03.2012

Name (Please Print)

J. ANTONJEN

Date 01.03.2012

Signature: Head of Institution (or other authorized signatory)

Signet

Contact Number 12712-521-11305

E-mail address Elsie.54@unisa.ac.za

OFFICIAL STAMP OF INSTITUTION

*Institution includes Universities, Hospitals, Research Institutes or Companies.

Executive Committee: Dr C. Mwantsambo (Chairperson), Prof. J. Mfutso Bengo (Vice-Chairperson) Registered with the USA Office for Human Research Protections (OHPR) as an International IRB IRB Number IRB000035969 FWA00005976 Email: mohdoccentre@gmail.com
APPENDIX D (a): A PERMISSION LETTER TO THE MINISTRY OF HEALTH AND POPULATION IN MALAWI

University of Limpopo-Medunsa Campus
P.O. Box 142
Medunsa
0204

The Chairperson
National Health Science Committee
Ministry of Health and Population
P.O. Box 30377
Lilongwe 3
Malawi

Dear Sir/Madam,

RE:REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY IN MALAWI.

I hereby write to request for permission to conduct a research study across the country.

My name is Esmey Mkwinda, a student at the University of Limpopo-Medunsa Campus pursuing PhD in Community Nursing Science. In fulfilment of this programme I need to conduct a research study and I intend to conduct the above study at three palliative care sites across the country. And have chosen to conduct a pilot study at Ekwendeni palliative care clinic which is in Mzimba district, Ndimoyo palliative care clinic in Salima district, Nkhoma palliative care clinic in Lilongwe district and Kamuzu Central Hospital palliative care centre clinic in Lilongwe district. My research study is entitled, “guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi”. The study will be done under the supervision of Dr M. L. M. Sengane and co-supervision of Prof S. Lekalakala-Mokgele.
Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve interviews and will not interrupt rendering of services at the clinics. Ethical considerations in the study will include confidentiality, privacy and informed consent. The proposal has been approved by Medunsa Research and Ethics Committee (MREC) and the National Research Council of Malawi. And will also seek for approval at the District Health Officer (DHO) of the concerned districts before data collection. Attached is my research proposal.

Your Assistance in this matter will be highly appreciated.

Yours Sincerely

Esmey Mkwinda
Student Number: 201117696
Telephone Numbers: 0999672324/0111924394
E-Mail: esmeym@gmail.com
Appendix D (b): Approval from Ministry of Health

Dear Sir/Madam,

RE: Protocol # 992: “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi”

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has reviewed and approved your application to conduct the above titled study.

- **APPROVAL NUMBER**: NHSRC # 992
- **The above details should be used on all correspondence, consent forms and documents as appropriate.**
- **APPROVAL DATE**: 14/03/12
- **EXPIRATION DATE**: This approval expires on 14/03/13

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC secretariat should be submitted one month before the expiration date for continuance review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the National Health Sciences Research Committee within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using standard forms obtainable from the NHSRC Secretariat is required before implementing any changes in the Protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on Telephone No. (01) 789314, 0858957 or by e-mail on doccentre@malawi.net
- **Other**: Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database.

Kind regards from the NHSRC Secretariat.

FOR CHAIRMAN, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE

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PROMOTING THE ETHICAL CONDUCT OF RESEARCH

Executive Committee: Dr. C. Mwansambo (Chairman), Prof. Msando Bongo (Vice Chairman)

Registered with the USA Office for Human Research Protections (OHRP) as an International IRB (IRB Number IRB00003905 FWA00005976)
Appendix E: Approval from Lilongwe District Health Office

University of Limpopo-Medunsa Campus
P.O. Box 142
Medunsa
0204

Lilongwe District Health Officer
Box 1274
Lilongwe
Malawi

Dear Sir/Madam,

RE: APPLICATION FOR APPROVAL TO CONDUCT AN ACADEMIC RESEARCH IN YOUR DISTRICT

I hereby write to seek your permission to conduct a research in at your institution.

I am a Malawian registered nurse doing PhD at University of Limpopo (MEDUNSA Campus). Research is one of the requirements before completing the course, hence I would like to conduct this research study as soon as possible. The proposal for this research study was approved by the MEDUNSA Research and Ethics Committee (MREC) and the project number is MREC/H13/2012:PG and it was also approved by the National Research Council of Malawi and the project number is NHRSC 992 as per the attachment.

The study is entitled “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWA) in palliative care in Malawi”. This study will be conducted under the supervision of the two experts namely:
1. Dr M. L. M. Sengane.
2. Professor S. Lekalakala-Moaka
e

The study will be conducted in three phases which are as follows:
Phase one: will involve data collection and analysis.
Phase two: will involve concept analysis and conceptualization and
Phase three: Will involve developing guidelines, describing and evaluating them.

Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve interviews and will not interrupt rendering of services at the clinic. Ethical considerations in the study will
include confidentiality, privacy and informed consent. See enclosed for a summary of my research proposal. Answers for questions concerning the study will be readily available.

My contact details in Malawi are:
Address: P/Bag 31, Lilongwe.
Telephone number: +265 (0) 9996 72324/+265 (0) 111 973 125
E-mail: esmeym@gmail.com

Yours sincerely,

Mrs Esmey Mkwinda
Appendix F: Approval from Salima District Health Offices

REF. NO. SLH/10/08  

FROM : THE DISTRICT HEALTH OFFICER  
SALIMA DISTRICT HOSPITAL  
P.O. BOX 53  
SALIMA.

TO : ESMAY MKWINDA  
UNIVERSITY OF LILIMPOPO MEDUNSA CAMPUS  
P.O. BOX 142  
MEDINSA 0204

Dear Madam

I am pleased to accept your request conducting Research Study in my district in respect to your PhD in Community Nursing Science. Ndimooyo Palliative Care Clinic where you have interest to conduct your study is indeed partner in health with our hospital.

Therefore, you are welcome to consult anything pertaining to your study during this exercise.

Yours Faithfully

E.I. Manthepa

SALIMA DISTRICT HOSPITAL REGISTRY  
2 & APR 2012  
P.O. BOX 53  
SALIMA.
Appendix G: Approval from Mzimba District Health Officer

The District Health Officer
Box 131
Mzimba
Malawi

Dear Sir/Madam,

RE: APPLICATION FOR APPROVAL TO CONDUCT AN ACADEMIC PILOT STUDY IN YOUR DISTRICT

I hereby write to seek your permission to conduct a pilot study in your district.

I am a Malawian registered nurse doing PhD at University of Limpopo (MEDUNSA Campus). Research is one of the requirements before completing the course, hence I would like to conduct the pilot study at Ekwendeni palliative care clinic in your district. The main study will be conducted at three sites across the country. The proposal for this research study was approved by the MEDUNSA Research and Ethics Committee (MREC) and the project number is MREC/H/13/2012:PG and it was also approved by the National Research Council of Malawi and the project number is NHSRC 992 as per the attachment.

The study is entitled “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi”. This study will be conducted under the supervision of the two experts namely:
1. Dr M. L. M. Sengane.
2. Professor S. Lekalakala-Mokgele

The study will be conducted in three phases which are as follows:
Phase one: will involve data collection and analysis.
Phase two: will involve concept analysis and conceptualization and
Phase three: Will involve developing guidelines, describing and evaluating them.

Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve
interviews and will not interrupt rendering of services at the clinic. Ethical considerations in the study will include confidentiality, privacy and informed consent. See enclosed for a summary of my research proposal. Answers for questions concerning the study will be readily available.

My contact details in Malawi are:
Address: P/Bag 31, Lilongwe.
Telephone number: +265 (0) 9996 72324/+265 (0) 111 973 125
E-mail:

Yours sincerely,

Mrs Esmey Mkwinda
APPENDIX 4B
LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH STUDY
University of Limpopo-Medunsa Campus
P.O. Box 142
Medunsa
0204

The Hospital Director
Kamuzu Central Hospital
P.O. Box 106
Lilongwe
Malawi

Dear Sir/Madam,

RE: REQUEST TO CONDUCT A RESEARCH STUDY AT YOUR INSTITUTION

I hereby request for permission to conduct a study on guidelines for nurses to support primary caregivers of PLWHA in palliative care in Malawi at Kamuzu Central Hospital palliative care clinic.

My name is Esmey Mkwindia, a student at the University of Limpopo-Medunsa Campus pursuing PhD in Community Nursing Science. In fulfilment of this programme I need to conduct a research study and I intend to conduct the above study at three palliative care sites across the country. And have chosen to conduct a study at your clinic. My research topic is “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi. The study will be done under supervision of Dr M. L. M. Sengane and co-supervisor Prof S. Lekalakala-Mokgele.

Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve
interviews and will not interrupt rendering of services at the clinic. Ethical considerations in the study will include confidentiality, privacy and informed consent. See enclosed for a summary of my research proposal. Answers for questions concerning the study will be readily available.

My contact details in Malawi are:
Address: P/Bag 31, Lilongwe.
Telephone number: +265 (0) 9996 72324/+265 (0) 111 973 125
E-mail:

Yours sincerely,

Mrs Esmey Mkwinda
APPENDIX 4

LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH STUDY

University of Limpopo-Medunsa Campus
P.O. Box 142
Medunsa
0204

The Manager
Ndii moyo palliative care centre
Salima
Malawi

Dear Sir/Madam,

RE: REQUEST TO CONDUCT A RESEARCH STUDY AT YOUR INSTITUTION

I hereby request for permission to conduct a study on guidelines for nurses to support primary caregivers of PLWHA in palliative care in Malawi at Ndii moyo palliative care clinic.

My name is Esme Mkwinda, a student at the University of Limpopo-Medunsa Campus pursuing PhD in Community Nursing Science. In fulfilment of this programme I need to conduct a research study and I intend to conduct the above study at three palliative care sites across the country. And have chosen to conduct a study at your clinic. My research topic is “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi. The study will be done under supervision of Dr M. L. M. Sengane and co-supervisor Prof S. Lekalakala-Mokgele.

Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve interviews and will not interrupt rendering of services at the clinic. Ethical considerations in the study will
include confidentiality, privacy and informed consent. The proposal has been approved by Medunsa Research and Ethics Committee (MREC) and the National Research Council of Malawi and the District Health Officer (DHO). Attached is my research proposal.

Your assistance in this matter will be highly appreciated.

Yours Sincerely

Esmey Mkwinda

Student Number: 201117696
Telephone Numbers: 0999672324/0111924394
E-Mail: esmeym@gmail.com

[Stamp: Approved 20/4/12]
APPENDIX 4C

LETTER TO REQUEST PERMISSION TO CONDUCT RESEARCH STUDY

University of Limpopo-Medunsa Campus
P.O. Box 142
Medunsa
0204

The Hospital Director
Nkhoma CCAP Hospital
P.O. Box 48
Lilongwe
Malawi

To Whom it may concern

Please assist Mr. E. Mkwindwa on academic research.

10/05/12

Dear Sir/Madam,

RE: REQUEST TO CONDUCT A RESEARCH STUDY AT YOUR INSTITUTION

I hereby request for permission to conduct a pilot study on guidelines for nurses to support primary caregivers of PLWHA in palliative care in Malawi at Nkhoma palliative care clinic.

My name is Esmy Mkwindwa, a student at the University of Limpopo-Medunsa Campus pursuing PhD in Community Nursing Science. In fulfilment of this programme I need to conduct a research study and I intend to conduct the above study at three palliative care sites across the country. And have chosen to conduct a study at your clinic. My research topic is “Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi. The study will be done under supervision of Dr M. L. M. Sengane and co-supervisor Prof S. Lekalakala-Mokgele.

Participants in this study will be provided with the information leaflet about the purpose of the study and its objectives and will include palliative care nurses, PLWHA and primary caregivers. The study will involve
interviews and will not interrupt rendering of services at the clinic. Ethical considerations in the study will include confidentiality, privacy and informed consent. The proposal has been approved by Medunsa Research and Ethics Committee (MREC) and the National Research Council of Malawi and the District Health Officer (DHO). Attached is my research proposal.

Your Assistance in this matter will be highly appreciated.

Yours Sincerely

Esmey Mkwindia

Student Number: 201117696/0111924394

Telephone Numbers: 0999672324/0111924394

E-Mail: esmeym@gmail.com
Appendix K (a): Information about the study

UNIVERSITY OF LIMPOPO (Medunsa Campus)

Dear Prospective participant,

I am Esmey Mkwinda, a Doctorate student at University of Limpopo (Medunsa Campus).
I am conducting a study entitled ‘Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

The purpose of the study is to identify the palliative care needs of PLWHA and the primary caregivers and the needs of palliative care nurses. This information will assist me to develop guidelines to support primary caregivers of PLWHA in palliative care in Malawi. Dr. Sengane and Professor Lekalakala-Mokgele at University of Limpopo will supervise the study.

To complete the research study, I would like to invite you to participate in this study. The information that you will provide will be audio-taped and then transcribed for verification with the supervisors and the independent coder. These will be the only people who will have access to the tapes and transcriptions. The results from the study will only be used for the academic report. The data from the study will be coded so that it is not linked to your name. Your identity will not be revealed while the study is being conducted, reported and published. The study data will be collected by the researcher (Esmey Mkwinda). The data will be audio taped, transcribed and stored in a secure place and will be erased after five years of completing the study. Informed consent will be sought from you to participate in the study.

Participation in this research is voluntary and you can choose not to answer any questions. You have the right to withdraw at any time without penalty. Once interviews have been conducted, I will come to meet you again to confirm the information that you provided. I hope that you will participate in this research because your views are very important to me.

The benefit of participating in the research study is that you have an opportunity to verbalize your needs, and there are no risks and discomforts in this study. However, if at any time during
the study you experience emotional distress from disclosure you can notify me but also withdraw from the study if you wish.

If you have any questions about the study and about being a participant in this study, please feel free to contact me on the following numbers: 099 967 2324 or 0111 924 394. The research committees of University of Limpopo and Research council of Malawi have approved the study.

I have discussed the above information with the participants. It is my opinion that the participant understands the risks, benefits and obligations involved in this study.

---------------------------------------- -------------------------------------
Mrs E. Mkwinda                                                                   Date
Researcher
Appendix K (b) Information about the study (Chichewa version)

UNIVERSITY OF LIMPOPO (Medunsa Campus)

ZOYENERA KUDZIWA ZA KAFUKUFUKUYU
Kwa otenga nawo mbali mu kafukufuku,

Dzina langa ndine Esmy Mkwinda, wophunzira pa sukulu ya ukadaulo ya University ya Limpopo (Medunsa Campus).
Ndipo ndikupanga kafukufuku wa ‘Zotsatira zomwe anamwino angathandizile osamalira wodwala a anthu omwe ali ndi kachilombo ka HIV/AIDS mugawo la paliyetivi ku Malawi.

Cholinga cha kafukufukuyu ndi choti ndidziwe zosowa za anthu omwe ali ndi kachirombo ka HIV, zosowa za owathandiza ndi zosowa za anamwino othandizira ndi za paliyetivi. Zotsatira za kafukufuku zidza thandiza wochita kafukufukuyu popanga Zotsatira zomwe anamwino angathandizile osamalira wodwala a anthu omwe ali ndi kachilombo ka HIV/AIDS mugawo la paliyetivi ku Malawi. Dr. Sengane ndi Professor Lekalakala-Mokgele waku University ya Limpopo ndi omwe akuyang’anira kafukufukuyu.


Kulowa nawo mu kafukufuku ndi kosawumilizidwa ndipo mutha kusankha kusayankha mafunso ena komanso kusiya kupanga nawo osapereka chifukwa Wopanga kafukufuku azabweranso akatha kuti amvetse zomwe munamuza Ndili ndi chikhulupiro kuti mulowa nawo mu kafukufukuyu chifukwa nkhani yanu ndi yofunika kwambiri kwa ine.
Palibe phindu lililonse lolowa nawo mu kafukufukuyu koma muzakhala ndi mwayi wonena zosowa zanu ndipo palibe choopsya chilichosne chopanga nawo kafukufukuyu.
Mutha kundiyimbila telefoni pa nambala izi ngati muli ndi mafunso: 099 967 2324 or 0111 924 394. Komiti ya University ya Limpopo ndi Research council ya Malawi yabvomereza kuti kafukufukuyu achitidwe.

Ine ndakambilana ndi otenga nawo mbali za kafukufukuyu ndipo amvetsetsa za cholinga chake ndi zotsatira zake.

----------------------------------------   -------------------------------------
Mrs E. Mkwinda       Tsiku
Dzina la opanda kafukufuku
Statement concerning participation in a Research Project.

Name of Study

Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi

I have read the information and the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name / and hospital number are not revealed.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this Study has been approved by the Medunsa Research Ethics Committee (MREC), University of Limpopo (Medunsa Campus) and The Malawi National Research Council Committee. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study

............................................................              .......................................................
Name of patient   Signature of patient

....................................         ........................         ........................
Place.          Date.                                Witness

Statement by the Researcher

I provided verbal and/or written* information regarding this Study
I agree to answer any future questions concerning the Study as best as I am able. I will adhere to the approved protocol.

...............................................   ....................................   ..............
Name of Researcher                Signature                        Date                           Place
APPENDIX 2

UNIVERSITY OF LIMPOPO (Medunsa Campus) CHICHEWA CONSENT FORM

Zomwe muyenera kudziwa potenga nawo mbali mu kafukufukuyu.

Dzina la kafukufuku: Zotsatira zomwe anamwino angathandizile osamalira wodwala a anthu omwe ali ndi kachilombo ka HIV/AIDS mugawo la paliyetivi ku Malawi.

Ine ndawerenga ndikuwuzidwa za cholinga cha kafukufukuyu komanso ndinapatsidwa mwayi wofunsa mafunso ndi nthawi yoganiza za kafukufukuyu. Cholinga cha kafukufuku uyu ndi chomveka bwino kwa ine ndipo sanandiumilize kuti nditenge nawo mbali.

Ine ndamvetsetsa kuti kutenga nawo mbali mu kafukufuku uyu ndikusankha kwanga, komanso nditha kusiya kupitiliza kutenga nawo mbali nthawi iriyonse osapereka chifukwa. Kutenga nawo mbali mu kafukufuku uyu sikudzakhudza kalandilidwe ka mankhwala a matenda omwe ndikudwala kapena kukhudza chisamaliro chimwe ndimalandira.

Ine ndikudziwa kuti kafukufuku uyu wavomelezedwa ndi komiti ya Medunsa Campus Research, Ethics and Publication committee (MREC) yomwe ili pa sukulu ya ukadaulo ya madokotala ya University ya Limpopo komanso wavomelezedwa ndi komiti yowona za kafukufuku ya Malawi National Research Council. Ndipo ndikudziwa kuti zotsatira za kafukufuku uyu zidzagwiritsidwa nthchito ndi oyang’anira kafukufuku komanso zitha kudzaulutsidwa. Ine ndikubvomereza kuti atha kugwiritsa nthchito ndiponso kuwulutsa zotsatira za kafukufuku uyu, bola chinsinsi chidzasungidwe ndipo pasadzakhale uthenga woze ndimalandira ine ndi mayankho anga.

Ine ndabvomereza kutenga nawo mbali mukafukufukuyu.

---------------------------------------------------------------
Dzina la otenga nawo mbali Sayini ya otenga mbali
---------------------------------------------------------------

Sitetimente ya wopanga kafukufukuyu

Ine ndapereka uthenga wa kafukufukuyu mu chikalata komanso pokambirana ndipo ndidzayetsetsa kuyankha mafunso omwe angakhalepo a kafukufukuyu. Komanso ndidzatsatira malangizo omwe tagwirizana za kafukufukuyu.

---------------------------------------------------------------
Dzina la opanga kafukufuku Sayini Tsiku Malo
---------------------------------------------------------------
Appendix N: Data collection tool for HIV/AIDS patients

**Biographical information for PLWHA to get background information**

Date:_________________ Site code_____________________

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ART Monitoring Check
Date diagnosed with HIV ----------------------------
Date started on ART----------------------------------
Condition since on ART-----------------------------
APPENDIX N (a): SEMI-STRUCTURED IN-DEPTH INTERVIEW GUIDE FOR HIV/AIDS PATIENTS ENGLISH VERSION

Title of the study: Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

CENTRAL QUESTION
Tell me about your needs in relation to care you receive from primary caregivers?

PROBING QUESTIONS
1. How can you describe your care in terms of:
   - Support from family members?
   - Support from nurses?
   - Support from your community?
   - Resources that you get to meet your needs?
   - Health services that you get from nurses and others who are involved in your care?

2. What do you wish could improve in the care that you get from primary caregivers?

3. What recommendations do you have for the primary care givers and nurses who provide care in order to meet your needs?

Is there anything else that you feel is important to discuss?

End of discussion.

Thank you very much for taking your time to share this information with me.
Appendix N (b): Semi-structured in-depth interview guide for HIV/AIDS patients chichewa version

Title of the study: Guidelines for nurses to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

CENTRAL QUESTION
Mungandiuze za zosowa zanu pa chisamaliro chomwe mumalandira kuchokera kwa achibale omwe amakusamalirani?

PROBING QUESTIONS
4. Mungafotokoze za chisamaliro mokhudzana ndi:
   - Thandizo lochokela kwa achibale?
   - Thandizo lochokela kwa anamwino?
   - Thandizo lochokela kwa anthu ozungulirana nayo?
   - Zinthu zomwe mumalandira kuti chisamaliro chikwane?
   - Zinthu zochokera kwa anamwino komanso anthu ena omwe amakusamalirani?

5. Ndi chani chomwe mumalakalaka chitasintha pa chisamaliro chochokela kwa achibale anu?

6. Munganene zotani kwa anamwino komanso abale okusamalani kuti zosowa zanu zikwaniritsidwe?
   Pali zina zofunikira zomwe mukufuna kuti tikambirane?

   End of discussion.
   Ndikuthokozeni chifukwa chotenga nthawi yanu kuti tikambirane.
### Biographical information for primary caregivers to get background information

Date: ___________________ Site code ___________________

**Sex**

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
</table>

**Age**

<table>
<thead>
<tr>
<th>18-25</th>
<th>26 – 30</th>
<th>31-40</th>
<th>41-50</th>
<th>51 -60</th>
<th>61 and above</th>
</tr>
</thead>
</table>

**Marital status**

<table>
<thead>
<tr>
<th>Single</th>
<th>Married</th>
<th>Widow</th>
<th>Other</th>
</tr>
</thead>
</table>

**Religion**

<table>
<thead>
<tr>
<th>Christian</th>
<th>Moslem</th>
<th>Other</th>
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</table>

**Level of education**

<table>
<thead>
<tr>
<th>No formal education</th>
<th>Primary school</th>
<th>Secondary school</th>
<th>tertiary</th>
<th>Other</th>
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</table>

**Language**

<table>
<thead>
<tr>
<th>English</th>
<th>Chichewa</th>
<th>Other</th>
</tr>
</thead>
</table>

**Occupation**

<table>
<thead>
<tr>
<th>Farmer</th>
<th>Teacher</th>
<th>Business</th>
<th>Retiree</th>
<th>Other</th>
</tr>
</thead>
</table>

**How long have you been the primary caregiver?**

<table>
<thead>
<tr>
<th>&gt;3months</th>
<th>&lt;3months</th>
<th>6months</th>
<th>1year</th>
<th>1year and above</th>
</tr>
</thead>
</table>

**Relationship to the patient**

Friend Husband wife Child Aunt Uncle Other

**Optional:** Their HIV status
Appendix O (a): Data collection tool (primary caregivers) (English)

Title of the study: Guidelines to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

SEMI-STRUCTURED IN-DEPTH INTERVIEW GUIDE FOR PRIMARY CAREGIVERS, ENGLISH VERSION

Date --------------------------------- Participants code number--------------------------------

CENTRAL QUESTION
Tell me about your needs in relation to care you give to your sick family member?

PROBING QUESTIONS
1. How can you describe your care in terms of:
   - Support from the nurses?
   - Support from the community?
   - Resources that you get to meet the patient needs?
   - Health services that you get from nurses and others who are involved in your care?
     Probe: education, skills in caring

2. What do you wish could improve in the care that you give the patient to meet the needs?

3. In what terms would you wish to be supported in the care that you give the patient?

4. What recommendations do you have for the nurses in terms of supporting you in care provision in order to meet your needs and the patients needs?

Is there anything else that you feel is important to discuss?

End of discussion.

Thank you very much for taking your time to share this information with me.
APPENDIX O (b): Data collection tool (primary caregivers) (Chichewa version)

Title of the study: Guidelines to support primary caregivers caring for people living with HIV/AIDS (PLWHA) in palliative care in some districts of Malawi.

Date --------------------------------- Participants code number--------------------------------

SEMI-STRUCTURED IN-DEPTH INTERVIEW GUIDE FOR PRIMARY CAREGIVERS (Chichewa version)

CENTRAL QUESTION
Mungandiuze za zomwe mumasowa posamalira wodwalayu?

PROBING QUESTIONS
1. Mungafotokoze bwanji za chisamaliro chanu pa njira izi:
   - Chithandizo chochokela kwa anamwino?
   - Chithandizo chochokela kwa anthu ozungulirana nawo?
   - Zomwe mumalandila kuti muthandize wodwalayu pa zosowa?
   - Chithandizo ndi zipangizo zochokela kwa anamwino ndi anthu ena okhudzana ndi kasamaliro ka wodwalayu? Probe: maphunziro, luso la kusamalira.

5. Inu mumalakalaka chani choti chisinthe pachisamaliro chomwe mumapeleka kuti mukwaniritse zosowa za wodwalayu?

6. Inu mumalakalaka mutathandizidzwa motani pa chisamaliro chomwe mumapereka?

7. Anamwino mungawauze zotani kuti muthandizidwe pa chisamaliro chomwe mumapereka kuti mukwaniritse kusamalira wodwalayu?
   Pali china chomwe mukufuna kuti tikambilane?

End of discussion.
Ndikuthokozeni chifukwa chotenga nthawi yanu kuti tikambilane.
Appendix P: Data collection tool for palliative care nurses

Title of the study: Guidelines to support primary caregivers of people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

Date: ______________  Site code _____________________

Biographical information for palliative care nurses to get background information

Age

<table>
<thead>
<tr>
<th>18-25</th>
<th>26 – 30</th>
<th>31-40</th>
<th>41-50</th>
<th>51 -60</th>
<th>61 and above</th>
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Sex

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<tr>
<th>Male</th>
<th>Female</th>
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<tr>
<td></td>
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</table>

Nursing Cadre

<table>
<thead>
<tr>
<th>Registered nurse</th>
<th>Enrolled nurse</th>
<th>Assistant nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Palliative care training

<table>
<thead>
<tr>
<th>Not trained</th>
<th>Two weeks training</th>
<th>Formal PC training</th>
<th>In training now</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

Employment condition

<table>
<thead>
<tr>
<th>Full time</th>
<th>Part time</th>
<th>Volunteer</th>
</tr>
</thead>
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<tr>
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</table>

Period worked in Palliative care

<table>
<thead>
<tr>
<th>&gt;3months</th>
<th>3 months</th>
<th>&lt;3months</th>
<th>&lt;6months</th>
<th>&lt;1year</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>

Other duties involved in ____________________________
FOCUS GROUP DISCUSSION GUIDE (FGD) FOR PALLIATIVE CARE NURSES

Title of the study: Guidelines to support primary caregivers caring for people living with HIV/AIDS (PLWHA) in palliative care in Malawi.

FGD Conducting date -------------------------------
Number of FGD -------------------------------
Number of FGD members----------------------- Area/District code---------------

This focus group discussion topic guide will be used to assist the researcher in collecting information from palliative care nurses. The focus group discussion guide is based on the research objectives. The FGD background information data sheet will be used separately before the discussion to collect information from each participant.

CENTRAL QUESTION
Tell me about your needs in relation to supporting primary caregivers of PLWHA in palliative care?
1. How can you describe your support in terms of:
   • Your knowledge and skills?
   • Guidelines that you follow?
   • Specific support that you provide?
   • Health public policies that you follow if any
   • Do you have any recommendations for this support to improve?
   • Tell me if other stakeholders support you as well
   • Probe: community, family members, management other health care workers

Is there anything else that you feel is important to discuss?

End of discussion.
Thank you very much for taking your time to share this information with me.
Appendix Q: Letter for the language editor

Kamuzu College of Nursing
P/Bag 1
Lilongwe

To: Mr P. Jiyajiya
Catholic University of Malawi
P.O Box 5452
Limbe- Malawi

Dear Sir,

RE: REQUEST FOR LINGUISTIC EDITING OF THE PHD THESIS FOR ESMIE MKWINDA

I write to request for linguistic editing of my PhD thesis titled “guidelines for nurses to support primary caregivers of people living with HIV/AIDS in palliative care in Malawi”.

Editing this document is a requirement by University of Limpopo before submission to the examination department as such I request this service from you based on your experience in English language. I would like to submit my thesis as soon as possible if your services are available.

Your assistance on this service will be highly appreciated.

Sincerely yours,

Esmie Mkwinda
Student number: 201117696
Appendix R: Letters having guidelines evaluation guide

TO WHOM IT WILL CONCERN

Dear Sir/Madam,

RE: APPLICATION FOR INPUT ON DRAFTED GUIDELINES FOR NURSES TO SUPPORT PRIMARY CAREGIVERS OF PLWHA IN PALLIATIVE CARE

I am Esmie Mkwinda, a Doctorate student at University of Limpopo (Medunsa Campus).

I am conducting a study entitled ‘Guidelines for nurses to support primary caregivers of People Living With HIV/AIDS (PLWHA) in palliative care in Malawi.

The purpose of the study was to identify the palliative care needs of PLWHA and the primary caregivers and the needs of palliative care nurses. This information will assist in developing guidelines for nurses to support primary caregivers of PLWHA in palliative care in Malawi. Dr. Sengane and Professor Lekalakala-Mokgele at University of Limpopo is supervising the study.

Guidelines have been drafted by the researcher based on the study findings and literature review as per attachment. These guidelines have been drafted following adapted WHO guidelines development and Evidence-Based Care Guideline Development Process. For completion of the
guidelines, I would like to request for your input on the drafted guidelines. The required input includes the following criteria:

1. Importance of the guidelines
2. Accessibility and generality
3. Language used and simplicity
4. Clarity and applicability
5. Any other important information

If you have any questions about the study, please feel free to contact me on the following contact details:
Address: Kamuzu College of Nursing, P/Bag 1, Lilongwe.
Telephone number: +265 (0) 9996 72324/+265 E-mail: esmeym@gmail.com

This study was approved by the research committees of University of Limpopo and Research council of Malawi. Your input will be highly appreciated. I hope that you will participate in this process because your views are very important to me.

Yours sincerely,

Esmie Mkwinda
Student Number: 201117696
Appendix S: Draft of guidelines for input from experts

Guidelines for nurses to support primary caregivers of People Living With HIV/AIDS in palliative care in Malawi

Aim of the guidelines: To provide guidance for nurses when assisting primary caregivers who care for PLWHA

Target users: Each and every nurse at all the health facilities

Background of the guideline development processes

A research study was undertaken in 2012 at three palliative care sites in Malawi where needs of primary caregivers of PLWHA were identified, needs of PLWHA and also needs of palliative care nurses. The needs of palliative care nurses were as follows: need for proper training, lack of resources, lack of support and lack of guidelines. In addition, the primary caregivers of PLWHA shared the following needs: need for knowledge in their role, need for clinical and financial resources and need for support in their role. Furthermore, the PLWHA shared the following needs: need for physical care, need for quality health care services, need for knowledge and need for resources and support with their condition. These needs were congruent to findings of a study by Candy, Jones, Drake, Leurent & King (2011); Hudson & Payne (2011), Payne, Hudson, Grande, Oliviere, Tishelman, Pleschberger, Firth, Ewing, Hawker & Kerr (2010) and Lee, Li, Jiraphongsa & Rotheram-Borus (2010) where evidence shows that good palliative care saves lives, health care resources but also reduces hospital admission. Based on these needs, it was recommended that primary caregivers should be supported by nurses according to their needs. The primary caregivers in this study are the guardians or people who care for the PLWHA and could be a relative, friend, child or parent. The nurses in this study are the ones who are found at different facilities and health care institutions who care for patients.

<table>
<thead>
<tr>
<th>Study results and literature review</th>
<th>Draft guidelines</th>
<th>Recommendations from experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support of palliative care nurses</td>
<td>Nursing management should ensure that adequate space for palliative care provision is provided which could include at least 2</td>
<td></td>
</tr>
</tbody>
</table>
palliative care nurses consultation rooms in a quiet and child friendly environment, proper waiting area, store room for medication and equipments

Management should allocate at least three nurses in palliative care each day so that quality care is provided to the patient and proper support of the primary caregiver. Provision of locum should be made available to ensure that adequate staff members are available.

Management should ensure that adequate stock of drugs is available in palliative care at all times which are for free especially pain killers such as morphine and vincristine drugs

<table>
<thead>
<tr>
<th>Need for support, input and monitoring from hospital and nursing management, DHO and MoH is required in order to achieve proper support of primary caregivers.</th>
<th>1. Hospital management should ensure that adequate space is provided for palliative care provision. This should ensure that privacy is maintained and enough room is available for consultation but also availability of a day ward for patients to rest and involvement of primary caregivers. This could include at least 2 consultation rooms in a quiet and child friendly environment, proper waiting area, store room for medication and equipments</th>
</tr>
</thead>
</table>

228
2. Nursing management should ensure that nurses are properly trained in palliative care before being allocated in palliative care. This training would be achieved if
   i. The nursing curriculum includes palliative care at all levels and nurses are trained in both theoretical and practical component of palliative care.
   ii. If on the job training is provided with the minimum duration of seven weeks for both theory and practical.
   iii. If the training includes pain assessment using different scales and management, conducting counselling, importance of supporting primary caregivers, needs of caregivers and the nurses role in supporting caregivers.

3. Nursing management should ensure that adequate staffing is available at all times to ensure that PLWHA are given quality care and proper support of primary caregivers.

4. Nursing management should identify the support needs of palliative care nurses and ensure
that they are mentored in their role by experienced colleagues.

5. Proper referral systems need to be provided to palliative care nurses for cases that they fail to handle and the primary caregiver need to be included in this process.

6. The MoH through hospital management needs to ensure that adequate resources for palliative care are available and lack of resources should be reported to the management for supply.

7. Nursing management should ensure that nurses in the other wards and palliative care have frequent meetings for debriefing, sharing experiences and supporting each other.

8. Nursing management should ensure that mentors are available for palliative care nurses for support both professional and psychological support.

<table>
<thead>
<tr>
<th>Supporting primary caregivers</th>
<th>Need for training of primary caregivers in their role</th>
<th>Nurses should assess the primary caregivers need for support on individual basis and consider the following areas:</th>
</tr>
</thead>
</table>

230
1. Primary caregivers should be educated on the following: treatment including ART, opportunistic infections such as kaposi sarcoma, cancer of the cervix etc, prevention of parent to child transmission of HIV, breastfeeding and prevention of infecting partners in sero-discordant relationship.

2. The need for visiting primary caregivers at home should be assessed and provided in order to supervise them in their role, teach them on specific needs and provide resources and psychological support in form of advice on caring and practical assistance.

3. The nurses should assess the patient and primary caregiver for knowledge on the patients’ condition and the required care on each visit and training in the caring role should be provided as necessary in order for them to improve their skills, and increase their confidence. This training could include how to provide physical care such as assistance with bathing, mobility, changing positions in bed and wound care.
and education on patient’s condition

4. The nurse should provide information on the patients’ condition and care to be provided by the primary caregivers which could include the following:

i. Information on the signs and symptoms experienced by the patient and opportunistic infections

ii. Education on treatment that the patient is getting and importance of compliance such as ART

iii. Physical care required by specific patients such as bathing, assistance with wound care, assistance with mobility and changing positions in bed.

iv. Education on nutritional requirements of the patient with six food groups using locally available foods

5. Nurses should show the primary caregivers how to provide physical care to the patient e.g bathing the patient, assistance with mobility, wound care and position changing

6. Nurses should teach the primary caregivers on how to prevent contracting HIV while caring for
their patients by using gloves.

7. Nurses should visit the primary caregivers at home in order to educate them and supervise their care.

8. Nurses should teach the primary caregivers and the patient on prevention of parent to child transmission of HIV as follows:
   i. Use of condoms during sexual intercourse
   ii. Use of artificial milk and avoidance of breastfeeding

9. Nurses should teach the primary caregivers and the patient on cancer of the cervix and its prevention as follows:
   i. The cause and those at risk
   ii. Signs and symptoms
   iii. Screening tests available such as Visual Inspection using Acetic acid (VIA)
   iii. The available treatment

10. Nurses should teach the primary caregiver and patient on preventing infections in sero-discordant relationship by advising them to use condoms at all times when having
sexual intercourse.

11. Nurses should encourage the primary caregivers to contact the nurses from the clinic if they require more information about patient using telephones and visitations.

<table>
<thead>
<tr>
<th>Assessment and provision of financial, clinical and other resources needed by the primary caregivers for quality care of the patient.</th>
<th>1. Primary caregivers need for resources should be assessed individually by nurses according to the patients needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Nurses should provide clinical resources such as gloves, bandages, cotton wool and sanitary pads to the primary caregivers for use during patients care.</td>
</tr>
<tr>
<td></td>
<td>3. Nurses should teach the primary caregivers on how to use different resources and encourage primary caregivers to come to the clinic if they run out of resources.</td>
</tr>
<tr>
<td></td>
<td>4. Nurses should ensure that PLWHA are provided with free ART and other prescribed medications according to the hospital protocol.</td>
</tr>
<tr>
<td></td>
<td>5. Primary caregiver financial status has to be assessed and need for support be identified for example</td>
</tr>
</tbody>
</table>
transport and hospital bills. Nurses should be acquainted with sources of financial assistance for the PLWHA of different institutions and refer patients and primary caregivers in need of financial assistance for proper management using proper channels.

6. Nurses should assess the need for nutritional supplements and provide them to the PLWHA according to the need but also teach the primary caregivers on additional foods that need to be given.

<table>
<thead>
<tr>
<th>Nurses should ensure that primary caregivers are supported</th>
<th>Nurses should assess the primary caregivers need for support on individual basis and consider the following areas:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>i. Involving the primary caregivers in the care during clinic visits and also when the patient is admitted for knowledge sharing and continuity of care at home.</td>
</tr>
<tr>
<td></td>
<td>ii. Primary caregiver and the patient should be provided with telephonic contacts of the clinic and palliative care nurses for communication if they need advice on the patients’</td>
</tr>
</tbody>
</table>
condition and constant communication should be available between the two parties.

1. Primary caregivers should be assessed for need of respite support and the identified clients should be provided with options such as family members, community members, volunteers etc.

2. Primary caregivers should be assessed for need of support from family members, community or the church and the needed support should be identified such as assistance with physical care or financial support etc. The family, community and church members should be informed about this need and be taught on provision of the specified support.

3. Nurses should ensure that communities have support groups for the patient and caregivers in order to share experiences, prevent isolation and offer emotional support.

4. Nurses should provide bereavement support to the primary caregiver
and this could encompass the following areas: reflection on the importance of her role and contributions to the health care systems, caring for her health and referral to organizations which could continue provision of financial resources.

5. The need for government support to primary caregivers should be identified on individual basis and this support should be able to benefit the patient and could include the following: loan provision, assistance with school fees, food provisions.

| 1. Provision of one stop clinic where patients access all services such as palliative care, family planning, ART which would save their time, money and ensure that continuity of care is achieved |
| 2. Patients should be treated promptly with proper assistance from nurses where they are not stigmatized by nurses |
| 3. Flexible health care appointments should be made available for the patients in conjunction with |
Effective team work is required between nurses, primary caregivers, doctors, family members and community members regarding care given to PLWHA.

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Palliative care nurses should assess the need to involve multidisciplinary health care team such as doctors, dieticians etc and this need should be communicated to the patient and primary caregiver and written in the patients file.</td>
<td></td>
</tr>
<tr>
<td>2. The role taken by other members of the health care team need to be written in the patients file in order to avoid duplication and everyone involved need to be notified of such.</td>
<td></td>
</tr>
<tr>
<td>3. Consent should be obtained from the patient and primary caregiver on the need to involve other family members and community members. The reason for involving the family members and community members</td>
<td></td>
</tr>
</tbody>
</table>
should be clear and communicated to both the patient, primary caregiver and all the parties involved and the role to be taken.

4. The palliative care nurses should assist in educating the family and community members on their role and expectation such as assistance with bathing.

5. If the patient request for support from church members, the message could be sent by the primary caregiver or the nurse if the patient is admitted and this involvement should be written in the patients file.
### APPENDIX T: GUIDELINES EVALUATION GUIDE

#### SIX DOMAINS AND APPLICATION OF GUIDELINES FOR QUALITY PRACTICE AND CRITICAL REFLECTION

<table>
<thead>
<tr>
<th>Domain</th>
<th>How it was applied</th>
</tr>
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<tbody>
<tr>
<td>Scope and purpose</td>
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</tr>
<tr>
<td>Stakeholder involvement</td>
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</tr>
<tr>
<td>Rigour</td>
<td></td>
</tr>
<tr>
<td>Clarity, simplicity and presentation</td>
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</tr>
<tr>
<td>Applicability and importance of guidelines</td>
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<tr>
<td>Accessibility of the guidelines</td>
<td></td>
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<tr>
<td>Editorial independence</td>
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