

Exploring the lived experiences of nurses caring for the terminally ill patients with AIDS in selected wards in a level one district hospital in KwaZulu-Natal.

by

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DECLARATION OF ORIGINALITY

I declare that:

Exploring the lived experiences of nurses caring for the
terminally ill patients with AIDS in selected wards in a
level one district hospital in KwaZulu-Natal,

is my own work and all the sources that I have used or quoted have been indicated
and acknowledged by means of complete references.

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ABSTRACT

Title: Exploring the lived experiences of nurses caring for the terminally ill patients with AIDS in selected wards in a level one district hospital.

Aim: The purpose of this study was to explore and describe the experiences of nurses caring for dying patients with AIDS in the context of palliative care.

Methodology: The study explored the meaning of caring and terminal illness and the lived experiences of nurses in the context of AIDS in palliative care. A constructivist paradigm underpinned this study. A qualitative research approach was used and Giorgi's five steps of analysis were aligned to the Husserlian phenomenology method to make sense of the data. Individual in-depth interviews were conducted with ten of the operational nurses who were caring for patients suffering from AIDS in the palliative care wards of a level one state-aided district hospital. These included professional nurses, enrolled nurses and enrolled nursing assistants. The interviews were audio-taped.

Findings: The findings of the study were presented and discussed according to the two categories that emerged during the data analysis, namely, conceptualization of the core concepts of caring and terminal illness and the experiences of caring in the context of palliative care. Each of these categories had themes and sub-themes that were presented and discussed. The conceptualization of the core terms influenced the nurses' actions, behaviors and opinions as they described their experiences of taking care of terminally ill patients who suffered from AIDS. The nurses' lived experiences were conceptualized into three main themes: the social networking that enabled the nurses to collaborate with colleagues in the interdisciplinary teams and share knowledge, skills and support within the palliative care team to optimize patient outcomes; factors hindering the nurses abilities to provide quality care to their

patients and the internal and external mechanisms that enabled the nurses to provide care within palliative care contexts despite the encountered challenges.

Conclusion: Nurses are exposed to increasing work-load in the context of HIV/AIDS, particularly in the care of terminally ill patients suffering from AIDS as they deal with complex emotional aspects of the diseases. Routine exposure to suffering and death accustom the nurses to dealing with death, resulting in situations where they display lack of care and respect for the terminal patients. Therefore, the antecedents that alter the nurses' level of caring augmented by the emotionally taxing contexts are an agenda that needs to be addressed in order to achieve emotional work through improved nurse-patient relationships.

Key words: Lived experiences, nurses, Caring, Terminal Patients, AIDS, Palliative care, level one district hospital

ABBREVIATIONS

HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
TB	Tuberculosis
MDR	Multiple Drug Resistant Tuberculosis
XDR	Extensive Drug Resistant Tuberculosis
PROMS	Patient Reported Outcome Measures
APCA	African Palliative Care Association
HPCA	Hospice Palliative Care Association
IMAI	Integrated Management of Adolescent and Adult Illness
PEPFAR	President's Emergency Plan for AIDS Relief
WHO	World Health Organization

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND

Globally, nurses, as the backbone in health care delivery, (Smit 2005), carry the responsibility of bringing health services to all communities through the spectrum of health care delivery (Nursing Strategy for South Africa, 2008). However, staff shortages in the profession impact negatively on access to health services and the quality of care that is recommended in the (National Health Insurance SA, 2011) which advocates health for all. Additionally, nurses have admitted that, due to the AIDS epidemic, they feel overwhelmed by the increasing number of terminally ill patients they care for, who tend to suffer from complications of the disease and need more specialized care than other patients, (Cullinan, 2006). The nurses' situation is compounded by their contextual issues which include, among other things, unmanageable workloads; managerial inadequacies, particularly in public hospitals; and the existing "paradigm of inequity" between the public and private health sectors (National Labor and Economic Development Institute, 2005:2; National Department of Health Strategic Plan (NDOH 2010-2013). The public hospitals are still affected by policies implemented during the Apartheid era which resulted in fragmentation of the health system and are characterized by deterioration of capital infrastructure, insufficient medical supplies, understaffing levels and overcrowded wards (District Hospital Service Package for SA, 2002).

The South African public hospitals are heavily challenged as it has been confirmed that over 80 % of the country's population have no medical aid cover and hence are forced to seek treatment in government clinics and hospitals (Cullinan, 2006). The

National Department of Health (2010-2013) in its 10 (ten) point strategic plan, estimated the costs on uninsured people in the public sector at R84 589 billion as opposed to R113 181 billion of insured South Africans in the private sector. Thus, there is a pressing demand to improve the quality of health services for all South Africans and eliminate the unnecessary gaps and disparities in health and health care service delivery, regardless of whether they are publicly or privately funded (National Health Plan, 1994; National Health Insurance SA, 2011).

Cullinan (2006) further explains that KwaZulu-Natal has the highest mortality rate of all the provinces in the country, with a percentage of 23.2%, followed by Gauteng at 18.4% and the Eastern Cape at 15.3% (Stats SA, 2006). This report also highlights that the total number of deaths (from all causes) have increased by 87% between 1997 and 2005. In addition, HIV/AIDS related deaths were reported the highest in SA among the natural causes of deaths occurring in hospitals at 76, 2%, (Stats SA, 2010). In 2008, a slight decline in HIV related deaths was noted, particularly in the age-group between 15-24 years, and the drop accounts to 3, 3% of deaths. HIV/AIDS, however, is ranked fourth among the 10 leading causes of natural deaths in the same age-group, (Stats SA, 2010).

The institution under study has shown a progressive increase in the number of people dying of HIV/AIDS. From January to March 2010, deaths per month were 5.3%, 7.6% 8.4% - average 7.1% - General mortality statistics in October to December 2011 reflect an increase in the mortality rate, 4.0% 11.0%13.0%. - average 9.3% (Hospital Stats, 2012). These statistics reflect the adult and pediatric patients from all wards in the 200 bed-hospital under study.

In many cases patients may not receive the quality care they need when they are sick, which can result in dissatisfaction, unhappiness and unnecessary loss of life. As can be expected, such conditions will have a negative impact on patients and their relatives (Yamagishi, Morita, Miyashita, Sato, Tsuneto and Shima, 2010). The escalating number of deaths was one of the factors that motivated the researcher to explore the nurses' lived experiences while caring for terminally ill patients with AIDS in order to understand the phenomena from their point of view.

Although 80% of the SA population makes use of the public health services, there is very little research focusing on the lived experiences of nurses in public hospitals (Pillay, 2010). This has been highlighted by Hopkinson, Hallett and Luker, (2003:526) who stated that *“significant improvements have been made in the understanding of death and dying, but from a perspective that does not focus on the experience of nurses.”* It is essential, therefore, to have some insight and understanding of the nurse's perspective in caring for terminally ill patients in hospital settings so that they can be provided with appropriate support.

A qualitative study was conducted by the National Labor and Economic Development Institute, (2005) to investigate the management of public hospitals in South Africa. The study took place over four years, in nine institutions within three provinces of South Africa. Eight of the institutions that participated in the study were tertiary (level 3) and regional (level 2) hospitals. The findings of the study revealed two major issues facing these institutions, namely operational and managerial issues. Operationally, the researchers found that due to the high population in urban areas, the public hospitals are highly stressed institutions. The heavy patient loads are due to, among other things, the HIV/AIDS pandemic, poverty and the inability of primary

health care clinics and district hospitals to cope with the patients before they reach secondary and tertiary institutions. The situation is exacerbated by a lack of managerial skills which are characterized by wasteful and ineffective managerial functions in terms of human and financial resources. However, it was noted that there were differences in the degrees of stress levels and that the hospitals with better resources were less stressed than those with limited resources. As concluded by the researchers, there is a need to restructure public hospitals, empower hospital management and find innovative strategies to increase staffing levels.

An interview report with the Chief Executive Officer (CEO) of the hospital under study, published by Cullinan (2003), echoed similar problems related to the burden of AIDS in the context of palliative care. In the report, the CEO acknowledged that, the hospital is struggling to deal with the impact of AIDS and, in an attempt to remedy this problem, the hospital had opened a palliative care facility to provide patients with access to pain relief and offer psychological, social and spiritual support. The number of beds for palliative patients has been substantially increased from 18 to 44 official beds. These figures, exclude the stretchers used as beds in the outpatient department.

Rooda et al, cited in Dunn, Otten and Stephens (2005: 97), recognize the principal role nurses play in the care of dying HIV/AIDS patients and their families. The authors also noted, however, that the care nurses provide to dying patients may be affected by their attitudes. This is supported by Lange, Thom and Kline (2008), who stated that the way in which nurses perceive death can either positively or negatively influence the care they give to terminally ill and dying patients. The nurses who see death as a necessary pathway leading to a happier life thereafter tend to show more

positive attitudes than those who fear to face death (Bernard, Rossitter and Cheung 2001).

A study conducted by Smit, (2005) on the perceptions of nurses in a public hospital, revealed that of all the health care professionals, it is mostly the nurses who have prolonged involvement in the care of people living with HIV/AIDS. Her findings showed that the majority of nurses experienced various issues which touched the personal, professional and structural aspects of their lives. These are highlighted below:

- Helplessness- is brought about by a sense of inability to help patients who are sick due to the fact that there is no cure for HIV/AIDS. This results in patients being discharged and sent home while they are still unwell and in need of hospitalization.
- Emotional Stress and Fatigue- Nurses have to care for patients in all stages of the disease from diagnosis to death and this includes meeting patients in varying phases of illness which poses a challenge for them to constantly adjust to the different needs of each patient and their families. In the long run this may lead to symptoms of burnout such as emotional distress, sense of weakening competency levels and physical exhaustion. This is worsened by job-related stress resulting from poor hospital infrastructure, inadequate equipment and lack of staff while at the same time struggling to meet the demands and expectations of nursing managers and hospital administration to provide optimum quality care.
- Fear and anxiety- is inherently linked to the risk of HIV/AIDS transmission resulting particularly from accidental exposure to needle prick injuries. If infected with HIV/AIDS, the nurses fall prey to being victims of stigma as

they would be suspected of involvement in irresponsible sexual practices. Fear and anxiety often hinder nurses from sharing painful work experiences with their loved ones, which, in turn, results in the bottled-up negative feelings of anger and frustration sometimes being misdirected to the patients and their relatives.

Research findings by De Villiers and Ndou, (2008) and Smit, (2005) have shown that negative emotions can lead to unethical behavior on the part of the nurses and their inability to create the therapeutic relationships of caring, mutual respect and trust necessary for the protection of the legal and ethical rights of HIV/AIDS patients. To address these issues, Tapsfield and Bates, (2011) have recommended ongoing institutional support in the form of in-service training about HIV/AIDS in order to reduce fears related to HIV transmission and ensure clinical competence. They also recommend that to provide appropriate high quality care to terminally ill patients in palliative care settings, counseling services should be offered to nurses to allow them the opportunity to verbalize their experiences, medical supplies should be provided and that nurses are given access to initiatives such as support groups and stress management courses.

1.2 PROBLEM STATEMENT

Nurses are the main group of health care workers who have regular and prolonged contact with people dying from HIV/AIDS (Smit, 2005 and Rooda et al, cited in Dunn et al, 2005:97). In view of the fact that no adequate treatment or vaccines have been found as yet for people living with HIV/AIDS (PLWHA), nursing care includes extensive physical care and rendering emotional support to these patients and their relatives (Cullinan, 2006). Consequently, nurses experience work-related stress,

exhaustion and burnout. In the South African context, this is aggravated by the deteriorating status of the public health sector, a sector which “*has been marked by poor capital infrastructure, insufficient equipment and heavy workloads,*” (Smit, 2005:23).

Research findings by (De Villiers and Ndou, 2008; Smit 2005) have shown that negative emotions lead to unethical behavior on the part of the nurses and their inability to create the therapeutic relationships of caring, mutual respect and trust necessary for the protection of the legal and ethical rights of HIV/AIDS patients. On the other hand, however, the public have high expectations of nurses, expecting them to render quality care for patients at all times, regardless of their illnesses, (Evian, 2000; WHO, 2003; USAID, 2009). Therefore, the researcher embarked to explore the lived experiences of nurses caring for suffering and terminally ill patients and to explore how these experiences impact on the daily personal and professional lives of the operational nurses in the context of caring for terminal patients with AIDS.

1.3 AIMS OF THE STUDY

The aim of this study was to explore and describe the lived experiences of nurses caring for terminally ill patients with AIDS in selected wards of a level one district hospital in KwaZulu-Natal.

1.4 RESEARCH OBJECTIVES

The objectives of the research were:

1. To explore the nurses’ understanding of the concepts of “caring” and “terminal patient”.
2. To explore the lived experiences of nurses caring for terminally ill patients living with AIDS.

3. To explore how the nurses' experiences influence the care they provide to terminal patients.

1.5 RESEARCH QUESTIONS

1. What is the nurses' understanding of the terms, "caring" and "terminal patient"?
2. What are the nurses' perceptions of their experiences in caring for terminally ill patients living with AIDS?
3. How do a nurse's experiences influence the care she/he gives to terminal patients?

1.6 SIGNIFICANCE OF STUDY

The significance of this study has been highlighted by de Araujo, da Silva and Francisco (2004) who maintain that death is acknowledged as a constant theme for reflection and discussion, whether on the biological or spiritual level. Kell and Walley (2009) re-iterate that in the context of AIDS related deaths, palliative care remains an essential part of HIV management, despite the increasing availability of antiretroviral treatment (ART) as part of the package of care for terminally patients with AIDS. Furthermore, palliative care plays a role in advancing the efforts to alleviating the physical, psychological and spiritual pain of people living with AIDS in developing countries (USAID, 2009).

In the South African context, this challenge is exacerbated by the increasing numbers of very sick and dying HIV/AIDS patients who tend to suffer from complications of the disease and may need more specialized care than other patients (Cullinan, 2006). This study may assist nurse managers and nurse educators to develop or incorporate educational programmes into their policies and

curricula that teach effective coping strategies aimed at preventing death anxiety among nurses, especially those with little or no experience in the care of dying patients and their families. It is strongly recommended that some understanding of palliative care issues is necessary for health care workers, particularly in developing countries where AIDS related deaths abound (Kell and Walley, 2009).

It is also significant in the sense that it will generate new knowledge and/or validate the existing knowledge in the context of the public institution and may contribute ideas for policy-makers in the wider public sector of the province, or identify new areas for further research. Furthermore, understanding the nurses' experiences gained by this study could inform social policies and programmes dealing with HIV/AIDS related care in South Africa and other countries with similar problems (Kell and Walley, 2009) and thus equip the nurses and other professionals with support and guidance in clinical practice through training in order to improve patient care (Bausewein, Simon, Benalia, Downing, Mwangi-Powell, Daveson, Harding and Higginson, 2011).

It is also hoped that the study will identify barriers that make it difficult for nurses to care for terminally ill patients and develop interventions to prevent or eliminate unnecessary fears and other responses to death which Bernard et al, (2001) summed up in their findings as feelings of helplessness triggered by the inability to help terminally ill patients, distancing themselves emotionally from patients and their families in order to diminish their own suffering, and general lack of knowledge and counseling skills. Discovering ways of dealing with the identified barriers may enable the nurses to provide quality care within a gratifying and rewarding environment. The study findings will also inform clinical practice with evidence-based service delivery

approaches and identify potential areas for further research within the context of caring for terminally ill patients with AIDS in the palliative care wards, (Bausewein et al 2011).

1.7 DEFINITION OF OPERATIONAL TERMS

Caring.

According to Leininger, (1991:1), “*care is the essence of nursing and the central, dominant and the unifying focus of nursing.*” In the context of palliative care, the focus of caring is based on a model of care that affirms life rather than death and managing the pain and symptoms of patients who are terminally ill with AIDS in order to maintain their quality of life. The meaning of care in this study refers to the interventions of the nurses in providing treatment for pain, symptom control and nursing care for patients diagnosed with AIDS.

Terminal patient or terminal illness

According to the research findings of Miller, Shield Mor, Teno, Lima, Smit, Grossman and Booth (2007:12), the six months prognosis associated with terminal illnesses, is not “*inherently meaningful and should be changed... as the prognostication is notoriously poor for many persons with chronic illnesses receiving long term care services.*” As has been described by the authors there are persons with terminal and or progressive chronic illnesses that might continue living for a much longer time.

In the context of this study, the concept refers to patients with AIDS, who are at an advanced or progressive stage. It must be noted, however, that although the general prognosis is poor due to the lack of a cure and that inadequate treatment may lead to death, some patients recover miraculously and live for a long time.

Ward

A hospital ward is described as a division of a hospital that is shared by patients who require a similar type of care, (Booyens, 2002).

In this study, the terms ward and unit are used interchangeably to relate specifically to the female and male medical wards allocated to palliative care by the institution under study.

Experience

Experience is described as the feeling of emotions and sensations as opposed to thinking and participation in the events and activities that enable the accumulation of knowledge and skills, (Mwamwenda, 2004). In this study, it relates to what the operational nurses do, see and feel. It also relates to the problems they encounter while caring for patients who are terminally ill with HIV/AIDS.

Palliative Care

The World Health Organization, (WHO), (2011:1) defines palliative care as

“an approach that improves the quality of life for the patients and their families facing the problem of life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment of pain and other problems, physical, psychosocial and spiritual.”

In this study, palliative care is understood as the provision of total care by the operational nurses which includes the psychosocial, physical and spiritual well-being of an adult patient suffering from a chronic illness such as HIV/ AIDS, and his/her

family, from the time of diagnosis until the death and bereavement phases, Bausewein et al 2011).

Operational Nurses

The Nursing Act (2003) describes a nurse as a person whose performance is based on knowledge and application of biological, physical and social science after having completed a course of training in an approved school of professional nursing. A nurse is required to be licensed under the nursing act to engage in professional or vocational nursing.

In the context of this study, operational nurses refer to all categories of nurses, that is, registered nurses, enrolled nurses and enrolled nursing assistants (as the latter are inclined to study further to assume full accountability in the nursing profession as registered nurses) who care for terminally ill patients with AIDS in the palliative care wards.

AIDS

AIDS is described as a syndrome of opportunistic infections that can develop as the immuno-suppression develops along the continuum of HIV infection from acute infection to death (UNAIDS, 2011).

In this study, AIDS refers to the end and terminal stages of HIV which are acknowledged as a most devastating and demanding public health problem.

Level 1 District Hospital

A level 1 district hospital is part of the district health system (DHS), which is the vehicle that improves the local health care needs of all people within the comprehensive Primary Health Care Services in South Africa, (District Hospital

Service Package for SA, 2002). The Health System's Trust (2011), notes that level 1 district hospitals have three critical roles to play in the health care system; that is, they provide support to the health care workers, delivery first level hospital care for those living in the district and refer patients to higher levels of care.

In the context of this study a level 1 district hospital is a hospital that receives patients from recognized primary health care clinics for further management.

1.8 CONCLUSION

This chapter outlined the background to the study and identified problems the researcher hoped to explore related to the lived experiences of nurses caring for terminally ill patients with AIDS in palliative care wards. The purpose and objectives of the research, the research questions, the significance of the research and the operational definitions were also explained.

The subsequent chapters will address the following topics:

Chapter 2 reviews the literature relating to the topic under study. These include the experiences of nurses caring for terminally ill patients, the issues in the care of terminally ill patients with AIDS, discovering meaning in life while caring for HIV/AIDS patients, and caring science in the context of palliative care.

Chapter 3 describes the methodology that is utilized in the study. The interpretive paradigm of the phenomenologists (based on Husserlian philosophy) is applied to the phenomenon under study, that is, the concept of caring and lived experiences. It includes descriptions of the study setting, the selection of participants, the criteria applied, the data collection tools and procedure, trustworthiness (issues of validity and reliability), data analysis according to Giorgi's Steps and ethical issues.

Chapter 4 provides the findings of the study and identifies the themes and sub-themes that emerged during data collection. These are discussed under the following two categories: i) the definition of the concepts of caring and terminal illness/terminal patient; and ii) care experiences in the context of palliative care.

Chapter 5 discusses the summary of the major findings of the study supported by the relevant empirical literature. It also addresses the limitations of the study and the recommendations.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Phenomenological studies vary according to the scope of the literature review and there are debates regarding the timing of when the review should be presented. Polit and Beck (2008) state that phenomenologists should undertake a literature review at the onset of the study in order to identify experiential descriptions of the phenomenon and to expand/enhance their understanding from different angles. However, Burns and Grove (2001:95) believe the literature review ought to be done after data collection to prevent phenomenologists from being influenced by previous findings, thus '*tampering with the researcher's perspectives on the research*'. This current study is aligned to Husserlian Phenomenology, which does not seem to have specific guidelines regarding the timing of the literature search. The researcher, therefore, decided not to conduct an extensive literature review prior to commencing the study, but rather to conduct a limited review to gather insight and enhance understanding of what is already known about the topic in order to guide the research process.

A more extensive literature review was done during the data collection and analysis phases of the research in order to assist in the identification and clarification of emerging themes and to guide the analysis process. Thus, at this stage of the study, the literature review will provide some information regarding the findings of previous research studies regarding the perspectives of nurses dealing with chronic care in oncology settings and quality of life as a core outcome of a palliative care setting.

Key concepts were identified to conduct the search, which included "experiences of nurses in public hospitals," "caring for dying patients," and "Nurses caring in Palliative

Care.” These concepts not only described the title of this study, but also set parameters to the researched topic. Thereafter, relevant sources of information were accessed from the University of KwaZulu-Natal Library, via the e-Link Catalogue (which can access all UKZN campuses) and the Federated Search (which simultaneously searches for multiple online databases). Electronic journals were retrieved using various different data bases, mainly African Health Line, AIDS Search, BioMed Central, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Pre CINAHL, Health sources, Consumer Editor, Health Source, Nursing/Academic Editor, MedLine, and Pubmed. In addition, off-campus links such as SA ePublications, ProQuest, Science Direct and BMJ Online were accessed. In order to obtain current information on the subject, selection was limited to articles published within the past ten years, that is, from 1/1/2002- 1/1/2012. Some of the related articles were older, but not prior to the year 2000.

2.2 PERSPECTIVES OF CHRONIC CARE NURSES IN ONCOLOGY SETTINGS

Although the transformation of the South African health system has progressed since 1994, the transformation of the regulation and practice of health professionals has not kept up with the pace, and of particular concern is the decline in the standards of nursing care among nurses (Nursing Strategy for South Africa, 2008). Nurses seem to have had difficulty in embracing the transition from curative care to palliative care, due to, among other things, lack of preparation in grief counseling and rigid unit policies (Bernard et al, 2001).

A qualitative study carried out in Brazil by de Araujo et al, (2004) aimed at exploring essential elements in caring for terminally ill patients. Their report emphasized the impact of caring for a dying patient. It also identified what is required of nurses caring

for terminal patients, the need for integral and humane care when death is imminent and the maintenance of effective communication with the dying patient. These concepts will be summarized and discussed in relation to the findings of other research.

2.2.1 The impact of caring for dying patients

The authors, de Araujo et al, (2004), noted that nurses' exposure to the suffering of patients and their relatives can bring about negative feelings, such as mourning, melancholy and depression. This is supported by Gill and Duffy, (2010) whose findings revealed nurses caring for patients with cancer found their work not only stressful but also challenging and emotionally demanding. The acknowledgment of the diverse needs of the patients with cancer and their families has led to an increased awareness for trained and educated nurses, so that they may be better equipped to address the needs of patients and their relatives through all the phases of cancers from '*diagnosis, treatment, potential recurrence and survivorship or potential death,*' (Gill and Duffy, 2010:761) so as to ease the negative impacts of caring for cancer patients. Dunn et al, (2005), who conducted a similar study on nurses' experiences and the care of dying patients, found that the nurses who had more contact with terminally ill patients tended to have more positive attitudes towards providing care for dying patients than those who had less contact.

2.2.2 What is expected of the nurses caring for dying patients

This domain focuses on the internal resilience of nurses who care for dying patients and was explained well by one of the nurses in the de Araujo et al, study who said, "*You have to have an emotional balance...otherwise you will not be able to do your job. You must interact with the patient maintaining constant contact with him/her and*

their family...or else you lose your balance,” (de Araujo et al, 2004: 152). On the other hand, if the inner strength or emotional balance to face death every day is challenged by other issues experienced by nurses moving from curative care to palliative care, they may develop defensive coping mechanisms to shield themselves from the emotional demands made upon them (Bernard et al 2001). This is particularly so among nurses who are not prepared for end-of life care (Li and Ng, 2008). However, Cunningham et al, (2006, cited in Gill and Duffy 2010: 766) suggest that for nurses caring for cancer patients to meet the expected quality of care with more confidence and competence, clinical and theoretical education should focus on topics related to the nature, prevention, diagnosis and treatment of the disease, as well as topics such as interpersonal communication, psycho-social support, death and dying, and organization and management.

2.2.3 The need for integral and humane care when death is imminent

This relates to the nurses' expressive role to impart care to patients as an inherent skill gained through their professional training. Cancer diagnosis is generally associated with helplessness, unbearable fear, pain and dying. Patients who have been diagnosed with cancer, therefore, may suffer psychological trauma and the nurses caring for them need to understand and identify patients' problems related to fear, stress, anxiety and changes experienced during cancer treatment, (Yildiz and Akansel, 2011). Furthermore, McWhan,(cited in Hopkinson, 2003:532) suggests that in order to achieve holistic care, it is essential that nurses are helped to deal with challenges they encounter, as this may improve the quality of their work with dying patients and assist them in continuing to render compassionate and humane care to suffering and dying patients.

2.2.4 Maintenance of effective communication with the dying patient

Research findings by de Araujo et al, (2004) revealed that some nurses found communication with a dying patient a challenging issue, which many avoided wherever possible by involving their seniors or the family as agents of patient care. In a qualitative study done in London by Li and Ng, (2008: 952), assessing nurse's experiences in caring for dying patients with profound learning disabilities, some nurses, who were interviewed, however, understood the value of verbal and non-verbal communication as enabling them to "*compare and contrast patient progress in the previous and current health status,*" in order to note deviations in their conditions. Good communication therefore, is accepted as a core value in nursing and is crucial for the delivery of quality oncology care as it may assist patients who may be distressed with cancer to integrate the disease into their lives, (Yildiz and Akansel, 2011).

It should be noted that most of the studies conducted in chronic care were Eurocentric, mainly focusing on cancer patients. In sub-Saharan Africa, a Hospital Based Palliative Care Review from Malawi and the Africa Project in Palliative Care have unanimously approved and highly recommended the importance of palliative care in an African setting (Tapsfield and Bates 2011; WHO 2011). These reports, have stressed that as palliative care improves the quality of life for all patients and families with life-threatening diseases including HIV/AIDS, the demand is even greater in the developing world, and as such, it is critical that palliative care should be implemented according to evidence based research, bearing in mind that:

- the majority of cancer patients need hospital care during the advanced stage of the disease;

- Palliative care has been recognized as adding a specific key role in the management of chronic conditions such as HIV/AIDS.

Consequently, in the light of the fact that few studies exist in the current literature relating to hospital based palliative care, (Tapsfield and Bates, 2011), the researcher has embarked on a study in the context of HIV/AIDS, in order to gain some insight and understanding on the lived experiences of nurses caring for terminally ill patients with AIDS in a palliative care wards.

2.3 QUALITY OF LIFE: A CORE OUTCOME OF PALLIATIVE CARE

Quality of life is recognized as an essential outcome of palliative care, and this can be evaluated by patients' social, spiritual, psychological and physical symptoms, (Selman, Higginson, Agupio, Dinat, Downing, Gwyther, Mashao, Mmoledi, Moll, Sebuyira, Ikin and Harding, 2011). Furthermore, Bausewein, et al, (2011) adds that to evaluate care interventions during palliative care service delivery, patient-reported outcome measurements (PROMS) can be used to assess patients' health and needs upon admission, to conduct audits for quality assurance purposes and for research. This intervention may improve palliative care outcomes by reducing unnecessarily prolonged stays in the palliative care wards, enhancing wellness and self-esteem and optimizing the sense of purpose among palliative patients receiving antiretroviral treatment (Jameson, 2007).

A study conducted by Selman et al, (2011) to examine the quality of life among patients receiving palliative care in South Africa and Uganda, revealed that patients scored close relationships, feeling at peace and having a sense of meaning in life as more important to their quality of life than being active and their physical comfort. These authors also identified some administrative, human resource and personal

issues identified by palliative care practitioners as major barriers to palliative care, such as lack of data to inform palliative care services, lack of training among palliative care professionals, reluctance to use PROMS and lack of time. In addition, tool-related problems were also reported, that they were either too long and thus not a true reflection of the patient conditions, or that the issues of reliability and validity were questioned if the tools were adapted and translated into different languages and cultures within the European and African contexts (Bausewein et al, 2011), thus failing in meeting the quality of life for palliative patients.

It was concluded that skills development and support on the use of existing tools were crucial for palliative care professionals (Bausewein et al, 2011) so that the spiritual and psychological needs of patients may be met with confidence and greater understanding of palliative care principles, which are aimed at sustaining the quality of life for dying patients (Selman et al, 2011).

2.4 THE DEVELOPMENT OF HOSPICE AND PALLIATIVE CARE IN SOUTH AFRICA

Clark, Wright, Hunt and Lynch, (2007) trace the history of hospice and palliative care in South Africa back to the 1970s, when about 60 organizations linked to the Hospice and Palliative Care Association of South Africa (HPCA) and were providing diverse services to patients and their families. The different types of services rendered included inpatient care, home care, day care, clinics/drop in-centers, hospital support teams, education and training, patient support groups, foster parent support groups, bereavement care, orphan support groups and hospice (Wright, 2004, cited in Clark et al, 2007). The Hospice and Palliative Care Association of South Africa (2010) has a mentoring role as a membership organization for the South African Hospices,

facilitating and coordinating the development of hospices and palliative care in the country.

According to Clark et al, (2007), the Hospice and Palliative care Association reported that between 2003 and 2004, 24 613 patients were treated as referrals from families, friends or state hospitals by its member hospices. Approximately half of these, that is, 12 413, had been diagnosed with AIDS and 9 233 were cancer patients. At present, 155 HPCA members care for over 60 000 patients and 180 000 family members every year at the 202 service outlets in South Africa (Hospice and Palliative Care Association of South Africa, 2010). In South Africa, unlike most African countries, palliative care services are also provided in hospitals throughout the country. Clark et al., (2007) listed the services they provide as follows:

- Clinical Management, providing early diagnosis (e.g. HIV testing), appropriate prophylaxis and treatment of opportunistic infections, as well as effective management of pain and symptom control.
- Nursing care, providing and maintaining hygiene and nutrition, teaching the family some basic nursing skills and emergency measures and supervising the taking of medication.
- Psycho-spiritual support, providing counseling and spiritual support including stress and risk reduction, as well as planning, promoting and supporting the acceptance and disclosure of serostatus and enabling coping and planning for the future of the family, particularly placement of children.
- Social support, providing welfare services and legal support, providing information and referrals between the partners who make up the care

networks, poverty alleviation, pastoral and bereavement care and facilitating peer support groups.

The South African hospices are committed to delivering quality palliative care to patients and families and protecting their reputation as quality organizations, (COHSASA/HPCA, 2009). To this effect, in 2005, the first edition of the Comprehensive Hospice and Palliative Care Standards, which is linked to the COHSASA/HPCA accreditation process, was distributed to all hospices.

South Africa has been supported since 2003 by the President's Emergency Plan for AIDS Relief (PEPFAR) and the Hospice and Palliative Care Association (HPCA) is also a beneficiary of this fund, (Clark et al, 2007). Although the HPCA has secured collaborative relationships and is currently working with other community organizations and government structures both nationally and internationally, the HPCA chief operating officer sent out notices to member organizations warning them that the USAID and HPCA contract would be ending in December 2012, (Hospice Palliative Care Association of South Africa, 2012). However, some international palliative care associations such as the African Palliative Care Association (APCA), the World Wide Palliative Care Alliance, (WPCA) and the Foundation for Hospices in Sub-Saharan Africa remain supportive in the global need for palliative care services to address HIV/AIDS, (Hospice and Palliative Care Association of South Africa, 2010).

2.5 TRAINING OF NURSES FOR HIV/AIDS CARE

With estimates of 33 million people living with HIV/AIDS globally (USAID, 2009), the demand for the expansion of the scope of practice for the nurses, driven by the escalating numbers of patients seeking care, will continue to increase as HIV/AIDS

programmes are scaled up, resulting in increased demands for training (Nursing Strategy for South Africa, 2008). In addition, the complexity of HIV disease management has necessitated greater provider collaboration and communication (Pillay, 2010), so as to promote the concept of task-shifting among the nurses with an aim of expanding the human resource capacity (Zachariah, Ford, Philips, Lynch, Massaquoi, Janssens and Harries, 2008). The need for training nurses is exacerbated by other challenges in the health care environments, which include staff shortages, lack of training (Nursing Strategy for South Africa, 2008; French, du Plessis and Scrooby, 2011), overcrowded public hospitals, inadequate managerial skills and lack of support by managers (Pillay, 2010; French et al, 2011). To improve access to antiretroviral treatment, a task shifting process is necessary, which includes development of standardized protocols/ clinical guidelines, simplified recording and reporting systems in order to decentralize the clinical interventions to lower categories of carers, such as from the doctors to the nurses and to the non-nursing personnel, (Zachariah et al, 2008).

According to the World Health Organization (WHO), (2009) over 6800 people become infected every day with HIV and more than 5700 die, mainly because they have no access to HIV prevention, treatment and care. Despite the progress made in government support programmes for national advocacy and accredited training support through USAID, the African Palliative Care Association (APCA) and the Hospice Palliative Care Association of South Africa in the past 2 decades (USAID, 2009), HIV remains the most challenging issue for the public health sectors (Selywn 2005; Kell and Walley, 2009), owing to inadequate skills among the carers, especially in sub-Saharan Africa where 67% of the men, women and children are living with HIV/AIDS, (USAID, 2009). These challenges impact negatively on the

nurses, as they end up doing tasks for which they have not received formal training, resulting not only in incompetency in the management of opportunistic infections, but also in poor quality care of patients (French et al, 2011).

However, Mockiene, Suominen, Vaelimaeki, Razbadauskas, Caplinskas and Martinkenas, (2011) argue that training interventions conducted for the nurses do not necessarily enhance their willingness to care for people living with HIV/AIDS. With a view to developing ongoing training programmes, a study conducted by these authors to ascertain the impact of educational interventions on nurses' willingness to take care of HIV positive or patients with AIDS reported the following findings:

- Minor changes were observed in a group of nurses after the formal training programme. This group had been willing to care for patients with AIDS even before the training, but after the training they seemed more caring of their patients and more willing to perform tasks such as cleaning the stools of incontinent patients and helping those who had problems with vomiting.
- The nurses in the control group, who received training materials with little personalized contact, were not willing to care for patients with AIDS.
- It was also noted that nurses with more work experience were more willing to care for patients with AIDS than the nurses with less work experience.

USAID, (2009), however, recognizes the need to implement formal training opportunities for all health care professionals, including medical doctors, nurses and lay caregivers, in order to develop their scientific and clinical management of

HIV/AIDS. Furthermore, through training and task shifting, the scope of practice for the nurses, midwives and other non-clinicians like the pharmacists, administrators or clerks will be extended in order to enable them to carry out some activities that were traditionally done by the doctors in attempt to relieve the challenges imposed by HIV/AIDS (Zachariah, et al 2008).

2.6 CONCLUSION

In summary, although the nurses' perspectives in the care of dying patients have been discussed broadly from diverse perspectives, most of the literature pertains to oncology settings in both industrialized and developing countries. It has been noted that caring for patients who are dying of cancer has an impact on nurses' experiences, which can be either negative or positive. However, very little research was available on palliative care within the South African context, and the need for palliative care services and training of nurses for AIDS care remains a global challenge in order to maintain the quality of life of patients dying of HIV/AIDS. In this study, the researcher is interested in using a qualitative approach to explore the experiences/meanings of caring for terminally ill patients among the various categories of nurses within the South African context, specifically in the palliative care wards of a public hospital in order to improve quality -care outcomes for both the nurses and the patients.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter will address the research methodology and the qualitative approach that were adopted for this study. It will further outline the research design, study setting, population, sampling technique and sampling size, data collection process, data analysis, trustworthiness of the research, ethical considerations and data management.

3.2 RESEARCH APPROACH

A constructivist paradigm underpinned this study. This paradigm supports the ontological (nature of reality) perspective of the belief that there is no single reality, but that multiple realities are constructed and can be altered by the knower (Laverty, 2003). According to this paradigm, "*phenomena are studied through the eyes of people in their lived situation,*" so, therefore, there is shared acknowledgement between the researcher and the participants (Weaver and Olson, 2006: 461). Epistemologically, this paradigm recognizes the interactivity between the knower and the known, thus values are linked in the creation of meaning. Methodologically, the study follows a process of interpretation and interaction between the researcher and the research participants (Laverty 2003). Based on this ontological and epistemological premise, the study revealed that the reality of the lived experiences of the nurses caring for terminally ill patients with AIDS was experienced in different ways which reflected the participants' constructed knowledge based on their beliefs, values and understanding of the core terms of caring and terminal illness within palliative contexts.

The aim of this research was to understand a human phenomenon, as it sought to explore and describe the lived experiences of nurses caring for terminally ill patients living with AIDS. This aim fitted with the philosophy and intentions of the constructivist research paradigm as it sought the nurses' contextual understanding in order to access the meanings participants assigned to their experiences as opposed to explaining or predicting their behavior as the positivist paradigm in quantitative research studies suggests. The researcher believed that the nurses caring for terminally ill patients have constructed unique ways in which they perceive what it means to care, which has been influenced by their frames of reference and the patients they serve.

It is believed that caring and experience are cognitive and interactive processes that are frequently implicit and subconscious and require an understanding of essential features of the phenomenon that are free from the influence of the external/cultural contexts, as they are mainly accessed from the participants' point of view (Dowling, 2007). These phenomena cannot maintain their essential embedded features if measured in quantitative research. Both caring and experience are complex phenomena involving multiple realities in terms of purposes and interpretation; there are no perfect approaches to caring and experiences. In addition, concepts are contextually bound, (that is, in terms of persons involved, the social and health situation and actual setting), therefore what is useful, relevant and meaningful depends on the situation. A constructivist paradigm was viewed as the most suitable for this research because of its potential to generate new understandings of complex multi-dimensional human phenomena such as those investigated in this research (caring and experience). Moreover, practical knowledge and information, which are otherwise embedded in the world of meanings, were gained and may assist nursing

managers and hospital administrators in formulating policies in palliative care or HIV/AIDS programmes.

Weaver and Olson (2006) are of the opinion that the interpretivist or constructivist paradigm is not without limitations as it tends to fail to take into account biological and social determinants of individual's actions, resulting in loss of objectivity. It is also noted that it is not always possible to explicate or unfold the researcher's intentionality. However, Rose, Beeby and Parker (1995), suggest that through the process of bracketing and awareness of personal ideas on the phenomena being studied, it may be possible to remain open and sensitive to the participants' views. For the purpose of enhancing the process of mutual sharing of information, Lochan Dhar, (2008) suggests that gestures of non-verbal communication, such as attentiveness illustrated with nodding, moving closer to the participant and maintaining eye contact may assure the participants that their contributions are taken into account and being attended to. In this study, the researcher displayed these gestures and facilitated participants' information with ease.

3.3 A QUALITATIVE APPROACH

A qualitative approach using the Husserlian phenomenology research method was used as it is useful in exploring the meanings of social phenomena as experienced by individuals in their natural contexts (Malterud, 2001). Qualitative research is complex and inductive and allows for free sharing of information or ideas between the researcher and the participants (Rose et al, 1995) as opposed to the narrow, reductive perspective of quantitative research (Burns and Grove, 1995). In addition, its focus is on discovery of new information, description and meaning rather than prediction, control and measurement (Laverty, 2003). The researcher believed that

with the use of Husserlian phenomenology, the participants would share their lived experiences from their conscious mind without being contaminated by the researcher's views, thus bracketing defended the validity of their world view. Was an appropriate method to use in this research as no previous study has been conducted which explored the nurses' experiences in caring for patients dying of HIV/AIDS within a hospital-based palliative care setting. This is apparent by the scarcity of literature available that is relevant to the South African context. The qualitative approach, thus, not only permitted the researcher to explore each individual participant's experiences in caring for terminally ill patients with AIDS, but also facilitated a descriptive discussion of the findings of the study.

3.4 RESEARCH DESIGN

The researcher specifically employed a phenomenological approach because she was interested in identifying, describing and understanding the subjective experiences of individual nurses with respect to the meanings they have regarding the care of terminal patients with AIDS. *"Phenomenology enquiry identifies the essence of a phenomenon and accurately describes it through the lived experience,"* (Rose et al, 1995:1123). Thus the philosophical approach adopted for this study was the Husserlian philosophy, owing to its main focus on understanding the meanings the participants assigned to their life situations, as experienced by them (Lavery, 2003).

The Husserlian phenomenology has an epistemological focus that acknowledges the nature of the relationship between the knower and the known, involving a *"rigorous and unbiased study of things as they appear in order to understand human experience and consciousness,"* (Dowling 2007:132). According to Husserl's

phenomenology, a study should focus on lived experiences in order to understand the meanings of human experiences as they are lived in everyday life, without attempting to categorize them (Laverty, 2003). In this study, the researcher explored and described the experiences of the different categories of nurses, that is, registered nurses, staff nurses and assistant nurses, who were caring for dying HIV/AIDS patients, as they were unfolded to her in their natural context within the palliative care setting.

In order to achieve this goal to the optimum interest of the subjects under study, the researcher employed the Husserlian methodological stance of bracketing and intentionality. In following this methodological approach, the researcher attempted to “bracket out” preconceived ideas and personal expectations resulting from previous work experience with dying HIV/AIDS patients (refer Appendix four), so as to focus on the participants in order to see the phenomena through their lenses (Rose et al, 1995). This paradigm was suitable for nursing research owing to the contributions it offers to its body of knowledge (Weaver and Olson, 2006; Laverty, 2003; Rose et al, 1995). There is some consensus among authors relating to the following benefits:

- This process has some benefits in that it eliminates some biases which could block the researcher’s ability of seeing and understanding the study based on the views of the subjects in their particular context;
- Its ontological perspective (nature of reality), holds the assumption that truth can be seen from multiple realities that are specific, local and holistic;
- The nature of this inquiry enables the research participants’ voices, concerns and practices to be made known (Malterud, 2001);

- Bracketing defends the validity (credibility) and objectivity (confirmability) of the interpretations against the researcher's personal advantage, (Laverty, 2003).

The qualitative methodology was used with an observational (specifically, the field notes), exploratory and descriptive design to collect data on the different categories of nurses, that is, professional nurses, enrolled nurses and nursing assistants in the male and female palliative care wards of the facility under study. The nature of this approach allowed the researcher to be actively absorbed in the subject of enquiry and to gain in-depth understanding through the detailed descriptions and explanations of the occurrences by those in the field (Malterud, 2001). Since this is a new topic that has not been researched before in this context, it provides an opportunity to observe the contextual issues and describe them as experienced by the participants. To this effect, it was deemed appropriate to conduct individual in-depth interviews during which non-verbal cues were also utilized in order to enhance the participants' unique experiences.

3.5 STUDY SETTINGS

This study was conducted in a level 1 district hospital. The hospital was initially established by a group of Trappist monks in 1882, but the hospital management was handed over to a Trust in the 90's. It is now a semi-private, 200-bed hospital (about 60% state-subsidized and 40% donor-funded). It is situated on the outskirts of Durban, KwaZulu-Natal, South Africa, and serves a population of approximately 700 000 people living in the Inner and Outer West Operational Entities of the Durban Metropolitan Area. It is the referral hospital for primary level of care for some 19

Government community clinics. As a district hospital, it provides outpatient care and level one generalist services to in-patients, rendering medical, surgical, obstetric and theatre services (for minor operations and caesarian sections) for adults as well as providing pediatric care.

As it is one of the district hospitals in the eThekweni District, service level agreements have been signed between the KwaZulu-Natal Department of Health and the hospital to operate as a “State” district hospital and approximately 60% of the hospital’s operational expenses are met by these agreements (Hospital Stats 2010). The balance is obtained through patient fees and fund-raising efforts, both in South Africa and abroad, from individuals, organizations, foundations and corporate entities.

The disease profile for the majority of the patients in the facility is related to opportunistic infections related to HIV and AIDS; malnutrition, gastroenteritis, TB and lower respiratory infections and they are often in need of extensive palliative care.

The palliative care wards were opened on a small scale in 2003 to provide services to 18 adult male and female patients suffering from AIDS. However, due to the need for chronic care of terminal patients, the number of beds has currently been increased to 44. Although these wards are not accredited to deliver palliative care services, the hospital has agreements with the Hospice Palliative Care Association of South Africa that they will provide training and supportive guidance to the staff working in these wards. As part of this relationship, a process of negotiations for an assessment towards accreditation of the palliative wards has begun and its completion depends on funding availability of the association. Thus, the researchers’

motivations for sampling this hospital for an exploratory study on the lived experiences of the nurses is hoped to identify opportunities and challenges that may highlight the pros and cons of such a process.

3.6 POPULATION

The population in this study included all the nurses (professional nurses, enrolled nurses and the enrolled nursing assistants) who were working in the palliative care wards of the institution under study. There are generally about 30 staff members working in these wards. Thus this number (N=30) is the accessible population, which is the group of people available for this study who met the criteria for inclusion (Burns and Grove, 2005).

3.7 SAMPLING TECHNIQUE

Sampling technique and sampling for the pilot study are described in this section to make the process followed more explicit as illustrated as follows:

The researcher aimed for a sample of between 10-15 nurses and they were selected through a purposive, non-probability sampling technique. The choice of face to face interviews encouraged the nurses to share the important aspects of their experiences and to expand freely on what was applicable to them (Polit and Beck, 2006). A small sample size was used as Lochan Dhar, (2008) suggested that Phenomenologists often depend on small sample sizes since data saturation (the point where the same responses are repeated, making data collection redundant) is the ultimate goal in this type of research, not the number of participants. The number can thus be approximately 5-15 people, whose ideas and experiences are needed to provide information for the specific study, (Brink, 2006).

A process of purposive sampling was used since it was important that all the informants had experienced the phenomenon under study and were willing to share their lived experiences with others (Lochan Dhar, 2008). Consequently, in this study the researcher selected informants who met the inclusion criteria and were able to provide the information that was needed for this research.

Table 3.1: Inclusion and Exclusion Criteria for sampling

Inclusion Criteria	Exclusion Criteria
1. Operational nurses (registered nurses, enrolled nurses and enrolled nursing assistants)	Non- nurses
2. A minimum of one year in the clinical settings working with terminally ill with AIDS.	Less than a year in the clinical setting and in terminally ill with AIDS.
3. Willing to participate	Not willing to participate

The operational nurses were used in this study for their potential to yield more information in order to understand the diverse experiences. The palliative wards in the study context are run by 2 registered nurses per shift, day and night with the majority of staff members being enrolled nurses and enrolled nursing assistants.

3.7.1 Sampling for the Pilot Study

A pilot study is a trial run aimed at testing or refining the study and correcting errors prior the main research to ensure that the study is trustworthy and produces consistent results (Polit and Beck, 2006). The trial study helps to clarify the feasibility

of the study at hand (Brink, 2006). The results feed information forward for the main study to enhance its credibility. A nurse at the hospital, who was trained in palliative care, was asked to participate in the pilot study.

3.8 DATA COLLECTION PROCESS

An overview of data collection process is described as an overview and the procedure followed explained as a sub-section as illustrated below:

When using the Husserlian phenomenological perspective, the process of data collection begins with self-reflection in order to be aware of one's own biases and assumptions so as to set them aside (Rose et al, 1995; Lavery, 2003). Consequently, the researcher undertook a values clarification exercise about caring, (explicitly written down into a journal for reference during data analysis) with a colleague prior to data collection. This was particularly necessary as although the researcher was lecturing at a nursing college during the initial stages of the study, she does have some clinical experience of caring for terminally ill patients. The process of phenomenological reduction assisted the researcher to focus on the phenomenon in its natural setting, seeing and understanding it for what it is, before imposing explanations or reflections on it which were likely to contaminate the study,

Instruments for data collection were the individual in-depth interviews, cues to facilitate probing during the interviews and field notes. A demographic question guide which focused on personal demographics and professional experiences was also used in order to provide objective and factual responses. All participants were presented with the same guide each time and, according to Klopper, (2008), this is a deductive strategy that is broad to specifics. The individual in-depth interviews allowed a purposeful conversation to take place in the exploratory study, especially

since the researcher did not have enough information of the phenomenon under study (Brink, 2006). As both the question guide and interviews were informal, the researcher maintained and facilitated a natural process of sharing information with the participants. Their statements were reflected back to them to ensure there were no misunderstandings and, if the researcher felt it necessary, certain probing questions were asked to seek deeper meaning and clarity of any unclear concepts (Brink, 2006). The cues and probing questions allowed participants time to elaborate on the study questions. A tape-recorder was used to capture their experiences more fully and to avoid any mistakes or misconceptions that might have arisen by writing it by hand.

The demographic question guide and the individual in-depth interviews are explained under sections A and B, respectively, below:

Section A: This section consisted of the demographic questionnaire which was used to identify the respondents and was made up of ten items. Different levels of scale-measurement were included such as the nominal scale with data fitting into categories like gender, race and the marital status, and the ratio scale-measurements which were characterized by mutually exclusive/exhaustive categories, rank ordering, equal spacing between intervals and continuum of values, e.g. age, and years of experience (Refer to Appendix Two on page 145).

Section B: This section consisted of the individual in-depth interview schedule, which contained open-ended questions based on the broad questions around the phenomena under study to encourage participants to give detailed accounts based on their personal knowledge and experiences. This section also included the probes

asked by the researcher during the face to face individual interviews that encouraged the participants to give more detailed descriptions of their experiences (Refer to Appendix Three on page 147).

The questions formulated in the interview schedule were guided by the literature review. The study conducted by De Villiers and Ndou, (2008) was of particular influence as it was similar to this study in that it explored the professional nurses' experiences caring for HIV/AIDS patients in the context of the risk of infection that is associated with the disease. While the current study focuses on dealing with death and dying patients, it is also within the framework of nurses caring for HIV/AIDS patients.

The field notes were in the form of a personal journal written by the researcher outlining the events that had been observed during each of the interviews with the participants, including non-verbal communication. As supported by Lochan Dhar (2008), the notes served as a second data source and also placed the researcher in the life-world of the study phenomenon. Hence, they were included in the descriptions of information about the non-verbal behaviors shown by the interviewees during the discussion of the data, (Refer Chapter 5).

3.8.1 Data Collection Procedure

Since this was an exploratory descriptive design, a qualitative approach was employed. Essentially, the objectives and the questions thought to facilitate the responses to the research objectives are illustrated in Table 3.2 below where each research objective has a corresponding question.

Table 3.2: Matching objectives to research questions

Research objectives	Research questions
1. To explore the nurses' understanding of the concepts of caring and terminal patient.	1. What is the nurses' understanding of the terms, caring and terminal patient?
2. To explore the lived experiences of nurses caring for terminally ill patients living with AIDS.	2. What are the nurses' perceptions of their experiences in caring for terminally ill patients living with AIDS?
3. To explore how the nurses' experiences influence the care they provide to terminal patients.	3. How does the nurse's experience influence the care she/he gives to terminal patients?

The researcher followed the following process: The participants were chosen through purposive sampling and the information document was explained to them. Once the participants had signed the informed consent, the demographic data was distributed to them for completion, which took between 5 and 15 minutes. The researcher collected the questionnaires and put them into a locked cupboard. Individual appointments were then arranged with each participant based on times that were convenient for them by the researcher. The rights of the nurses were respected and those who did not wish to be interviewed were replaced with newly recruited members, who had been selected by the researcher and contacted face-to-face. The ground rules were discussed with each participant to allow every one space to be relaxed. Each interview took 45-60 minutes. Participants were informed that an audio-tape would be used to minimize interruptions with the writing of notes and consented to the process. Cassettes were inserted into the tape from a zero count

and were changed when they were finished after the beep sound indication. In order to minimize threats to the internal validity of the study, that is, the Hawthorne effect whereby participants behave in an unusual manner based on their heightened awareness of participating in a study, the interviews took place in an environment familiar to them, such as the counseling room or offices, which were chosen by them. Lochan Dhar, (2008) confirms that an environment where the participants are comfortable it is more likely to produce rich and essential information.

Field notes were taken by the researcher after each interview noting the conversation that took place when the audio-tape was off and also non-verbal communication in order to enhance the participants' understanding of their unique experiences. Interviews continued until the 10th participant when data saturation had taken place. Saturation was established when emergent concepts on caring, terminal illness and the experiences in palliative care contexts were recurrent among the participants. Counseling services and de-briefing were offered for those who had discussed painful experiences during the interviews.

Most of the participants were interviewed only once, but for clarification purposes, follow-up interviews were done where necessary, as with participant two and participant four. These participants were contacted telephonically to request another interview and make the necessary appointment. The interviews were audio-taped and transcribed manually by the researcher.

3.8.2 Description of participants, settings and interview processes, and synthesis of field notes

3.8.2.1 Description of participants

The researcher interviewed a total of ten nurses working in the palliative care wards of the institution under study. A pilot study had been conducted with one of the nurses at the hospital who was not taking part in the study in order to check the feasibility of the study. This particular nurse had a wide experience of terminal patients and her input was very informative. Hence, the researcher was comfortable to proceed to the interviews.

For the sake of confidentiality all the participants were asked to choose a pseudonym, which was then used throughout the research. All the participants have had at least one year's experience in working with terminal patients and represent all categories of operational nurses. In this way, the inclusion criteria for this study have been met. Two of the staff nurses, participants 4 and 6, have had two years' exposure in these wards. The registered nurses had varied years of experience in palliative wards, mostly ranging between two and seven years, but two of them had been nursing terminal patients for about 20 years. All of the registered nurses, that is, participants 1, 3, and 8, 9 and 10, worked both in the female and male wards. The details of each participant are presented below.

Participant 1:

She is a 62 year old Xhosa speaking black female from the Eastern Cape. She belongs to the Roman Catholic Church. She is a professional nurse and midwife with 42 years of experience in the clinical arena, half of which (22 years) were spent with terminal AIDS patients. She has worked, and still works in both male and female wards, and is currently the unit manager of a 44 bed medical ward. She was very

enthusiastic about her participation in the study. She stays in KwaZulu-Natal for work reasons.

Participant 2:

She is a 26 year old, siSwati speaking female. She is an assistant nurse with one year's experience, mostly in female medical ward. At the time of study, she was currently enrolled at the nursing college to further her studies into becoming an enrolled nurse. She is a black religious sister from Swaziland, belonging to the Roman Catholic Church. She came to the study institution with a study permit for nurse training.

Participant 3:

This participant is a 34 year old Zulu speaking, black female. She is a local Roman Catholic religious sister and is based in KwaZulu-Natal. She joined an international congregation that was started in South Africa. She is also a professional nurse with four years of experience in male and female wards.

Participant 4:

She is a 24 years old Zulu speaking, black female, based in KwaZulu-Natal. She is a Christian and not married. She is a staff nurse (Enrolled Nurse) and has two years of experience in female wards. She had a follow-up interview to clarify some of her concepts related to her understanding of terminal illness that surfaced during the initial interview.

Participant 5:

She is a 23 year old Sotho speaking female from Lesotho. She belongs to the Roman Catholic Church and is single. She is an enrolled nursing assistant and has had one year's experience in male wards. She came to KwaZulu-Natal for study purposes and she is currently pursuing her studies to become an enrolled nurse in the study setting.

Participant 6:

This participant is a 24 year old Zulu speaking black female from KwaZulu-Natal, one of South Africa's nine provinces. She is not married. She is an enrolled nurse with two years of experience in both female and male wards. She had just completed a palliative course and implements these skills in the care of patients with AIDS.

Participant 7:

She is a 30 year old Sotho speaking, black female. She is from the Eastern Cape Province and stays in the study's institution for work reasons. She is not married and belongs to the Roman Catholic Church. She has three years' experience in working with male and female patients with AIDS. She is an enrolled nurse who wishes to continue her studies and become a professional nurse in the same institution of the study.

Participant 8:

She is a 36 year old Zulu speaking, black female from KwaZulu-Natal. She is a young single woman belonging to the Roman Catholic Church. She is a professional nurse with seven years' experience in male and female wards. She aspires to continue her studies to become a registered midwife.

Participant 9:

He was the only male working in the palliative care wards at the time of study. He is a 27 year old Zulu speaking, black male. He belongs to the Roman Catholic Church and is not married. He is a Professional Nurse with three years of work experience with AIDS patients in both male and female wards.

Participant 10:

She is a 62 year old white female. She is originally from England, but now has permanent residence in KwaZulu-Natal. She is married and belongs to the Protestant Church. She is a professional nurse with almost 25 years of experience, 20 years of which were with terminal patients, both male and female.

The participants were all currently working in the palliative care wards of the institution. They represented the cultural diversity of KwaZulu-Natal and included a Swazi, two Sothos, five Zulus, a Xhosa and an immigrant from England. In terms of gender, there was one male and nine females, thus making up the ten participants, excluding the additional one for the pilot study. Most of the participants were aged between 23 and 35 years old, with the youngest being 23 years old. The most senior participant was nearly 63 years old.

Once the information document had been explained to them, the participants were very enthusiastic about the research. Some were very eager to participate and asked the researcher, *"When will you interview me?"* One of the participants summed their enthusiasm beautifully, saying *"It is touching me this interview, because I am talking about something that I want to talk about..."* (Participant 1).

In terms of qualifications, all the registered nurses except one (Participant 1, who had a diploma in midwifery), were only qualified with a diploma in general nursing. They all mentioned that they wished to study midwifery in the following year.

3.8.2.2 The settings and interview processes

The hospital formed the setting of the study. The information document was explained at the nurses' station, thus introducing the study. Most of the individual interviews took place in one of the offices, but a counseling room was also used for the convenience of one of the participants in order to be near the ward for the patients. The purpose of the study was re-iterated to each of the participants in keeping with the ethical requirements. Informed consent (written) to take part in the study was obtained from each participant and these were signed before conducting the interviews. The consent form included permission to use the audio tape to record the interview. The voluntary nature of participating in the study and matters pertaining to confidentiality were emphasized at the start of each interview. Pseudonyms were chosen by the interviewees. The majority of the participants were punctual in observing the appointments times and apologies were forwarded by those who felt they could not come to the interviews due to unforeseen circumstances in the wards. Dates were re-scheduled for these exceptions.

The chosen environments were usually quiet and conducive for a face-to-face interview and when it was bitterly cold a heater was switched on to ensure the participants' comfort. There were interruptions on a few occasions, however, such as noise during visiting hours or the participant having to attend to a telephone call. These occurred more frequently when the supervisor's office or the counseling room, both of which are near a ward, were used. These interruptions did not seem to

disturb the participants, however, as they resumed the interview after dealing with the interruptions without the researcher having to repeat the questions. When such interruptions occurred the interview was halted and the tape recorder turned off until the situation was resolved.

3.8.2.3 Field Notes

Field notes were compiled into a journal during and immediately after the interview (Refer Appendix Eight, 7.8 on page 158). The field notes provided the researcher with information regarding the verbal and non-verbal communication patterns of the participant, and on the quality of rapport established with the participant. The field notes also included basic information such as time and place of the interview.

Although the participants were very eager and voluntarily participated in the study, a synthesis of the field notes with regard to the verbal and non-verbal communication of the participants revealed that a few of them were uncomfortable discussing matters pertaining to hospital management. This was verbalized by one of the participants who said, *“I do not like talking about my superiors....but there is a senior person in my unit who always looks at negative side of things. she comes in the unit and finds little and insignificant things that are not done, e.g. one bed that is not made properly, and makes a noise,”* (Participant 4). In such situations, however, the participants were encouraged to express their experiences because their descriptions were important to the nature of the study. One of the participants made the recommendation that management support was needed, saying with tears in his eyes, *“We need the management to support us in all ways possible,”* (Participant 6). Their discomfort was noticeable through avoidance of eye contact, fidgeting with jewelry (ear rings, rings), adjusting items of clothing, or rubbing their ears and eyes.

Overall, the participants displayed positive attitudes throughout the interview process. The researcher attempted to create good rapport with the participants by showing listening techniques such as nodding, attending and verbal confirmations like “mmm...mmm.” In addition, the researcher attempted to maintain appropriate eye contact, summarize, paraphrase and mirror verbal and non-verbal patterns throughout the interviews. It was noticed that such gestures facilitated the conversations or encouraged the participants to share their experiences freely and with ease, as evidenced by the amount of data that was obtained.

3.8.2.4 Difficulties experienced in data collection

The researcher did encounter a few challenges in carrying out the research. For convenience purposes, it was agreed by the researcher and the participants that it would be a lot easier to conduct the interviews during working hours. Although this proved successful for the enrolled nurses and nursing assistants, it was problematic for the registered nurses as it was difficult to find an appropriate time when they were not too busy in the wards, causing them to cancel the scheduled interview and rearrange the time. They were eventually interviewed in the early afternoons. In addition, two of the nurses who had agreed to participate and had already signed the information document were moved to other units. The researcher solved this problem by explaining the object of the study to the night staff who met the criteria for being participants into the study. A staff nurse and a registered nurse volunteered willingly. All interviews were conducted in an empty office except for Participant 8, who used a counseling room so as to be near her ward since she could not leave the ward unattended.

Some of the participants found it difficult to describe their experiences, especially in the early stages of the interviews, and were inclined to be more general by using pronouns such as “we” or “you,” or be too general in their descriptions. For example, “*you find yourself in a hard situation,*” (Participant 1) and “*a nurse must be strong, well equipped with knowledge, skills, knowing that the patient is completely surrendering everything to her/him*” (Participant 7). As the interviews progressed, however, they became more at ease, recounting stories that were more personal in nature, such as, “*...as I cared for my mother, it was hard, being from the rural areas because we never heard much about HIV/AIDS... Since I helped her, it’s easier to help someone who is not my relative,*” (Participant 2).

Another difficulty that was experienced was the ringing of cell-phones during the interviews. Although one of the ground rules that was clearly explained to the participants was that cell phones should be put on silent/vibration mode, there were about two occasions when the phones rang during the interview process and were answered by the participants. They did, however, resume the interview where they had left off prior to the interruption.

3.9 DATA ANALYSIS

As this study was qualitative, descriptive and exploratory in design, data was analyzed using the Phenomenological Data Analysis Method according to Giorgi’s (1985) five steps, as illustrated by Pallikkathayil and Morgan, (1991), Table 3.3 illustrates the steps that were followed:

Table 3.3: Data analysis process and application:

Step No.	Theoretical process	Application
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one	Reading of the entire disclosure of the phenomenon straight through to obtain a sense of the whole	Readings were done repeatedly on the transcripts after each interview to obtain emerging themes.
two	Re-reading the same disclosure again in a purposeful manner to delineate each time that a transition in meaning occurs. This is done with the intention of discovering the essence of the phenomenon under study. The end result is a series of meaningful units or categories.	The researcher met with a colleague to read and review the coding (categorization of data for analysis) process. Consensus was reached on unclear information. Clarity was also sought on follow-up interviews.
three	A: Examining the previous determined meaning units for redundancies, clarification or elaboration by relating meaning units to each other and to a sense of the whole. B. Reflecting on the meaning units (still expressed essentially in the language of the subject) and extrapolating the essence of the experience for each subject.	The meaningful units or categories were examined and those not related to research questions/ unique themes were noted as such.
four	Transformations of everyday expressions into psychological language: Systematic interrogation of each unit is undertaken for what it reveals about the phenomenon under study for each subject. During this process, each unit is transformed into the language of psychological science when relevant.	Reflections were done on the identified categories (data grouping based on similarities and develop sub-categories) and narrative capturing the essence of the phenomenon under study was formulated.
five	Formalizing a consistent description of the structure of the phenomenon under	Decisions were made on what to accept as common

	study across subjects by synthesizing and integrating the insights achieved in the previous steps.	experiences for the phenomenon. Relevant literature was used to support participant's information.
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In short, the information obtained from the participants during the data collection phase was recorded using a tape recorder and transcribed manually by the researcher, who subsequently checked the information with the participants and a colleague. This promoted objectivity, thus ensuring that the process was unbiased so that specific meanings and themes could be picked up and analyzed accordingly.

3.9.2 Analysis according to Giorgi's (1985) steps and discussion of findings

The researcher manually transcribed each of the taped interviews into text and then checked the transcriptions against the recordings. Although this process was time-consuming, it was also very beneficial as it enabled the researcher to become immersed in the text and the narratives of each participant. Having thus immersed herself, the researcher attempted to apply the theoretical process of data analysis as spelled out in Giorgi's five steps which involved: (i) getting the general sense of the whole statement; (ii) re-reading the text for the purpose of delineating meaning units focusing on the phenomenon being studied; (iii) relating the meaning of the units into each other and the sense of the whole; (iv) transforming everyday expressions into psychological language; and finally, (v) synthesis of the transformed meaning units into a consistent statement of structure (Refer Chapter 5). Each of the participant's data was read repeatedly and relevant codes were identified by the use of highlighters and different pens.

The process of application of these steps into the research is illustrated below as follows:

3.9.2.1 Step one: Getting the general sense of the whole

This step involved listening to audiotapes and reading the transcribed interviews. During this process, the researcher tried to understand the participants' information by being conscious of her own experience in the care of terminally ill patients with AIDS. This awareness helped her to avoid allowing personal experiences/ pre-conceived ideas to get in the way of the participants' descriptions (Refer Appendix Four, 7.4)

Each interviewee's data was approximately four pages which in total constituted forty one (41) pages. These were then grouped together with each of them containing all the necessary information such as pseudo name, age, date, place and time of interview, and were printed out for easy reading (Refer Appendix Eight on page 158). When the researcher felt overwhelmed with the participants' information, she would put it aside for a while and then take it up again as often as necessary so as to get a sense of the whole (Giorgi 1985), which in this study was participants' unique experiences in the care of terminally ill patients. Their experiences at this stage were noted holistically, with nothing being highlighted or discarded as irrelevant as it was important to note the essence of the whole picture of what caring for terminal patients meant to them as they each shared their experiences obtained in the palliative care wards. They described some pleasant experiences and some difficult experiences and the way in which these had either positively or negatively influenced the care they had given to the patients. They also described some of the factors, both supportive and hindering, that contributed to the quality of care they were providing to their patients.

3.9.2.2 Step two: Discrimination of meaning units

This step involved re-reading the transcripts once the essence of the whole had been perceived to extricate meaning units with a specific focus on the phenomenon being studied. Giorgi's concept of "meaning units" was helpful in facilitating this process. As it was difficult to analyze the entire text at once, it was practical to split it into more manageable units. Thus through reading and reflection and focusing on the phenomenon under study, that is, nurses' experience in caring for AIDS patients, a total of 41 meaning units were identified from the 10 participants, (Refer Appendix 7.10). In essence, this meant that each participant had an average of four and half meaning units. The researcher then studied them further and identified the constituents that would be relevant for the study. They were then re-grouped according to intertwining meanings, as illustrated below.

Six constituencies were identified by grouping participant's words that were related to each other. These are displayed below with the related words in brackets:

1. Definition of the concept of caring: (value, essential, core to nursing)
2. Care activities: (listening, love, putting yourself in other's shoes, be the mind of the patient, total, sacrifice, all encompassing).
3. Caring is influenced by the background of the participants: (evolving disease, care started at home).
4. Challenges related to care: (fear of infection, criticisms, annoying patients: (these limit care, as it becomes hard, uneasy).
5. Characteristics inherent in care: (God as provider of protection, resources minimize tension, communication and support (in the MDT (multi-disciplinary team), and patients).

6. In terminal care: (defined as poor prognosis, hard to recover, ill and dependent need to be assisted with peaceful death, they are in their last stages of life, but some may live longer), interventions (nothing can be done to them, making care monotonous), helps to think about own death. AIDS is an opportunity.

3.9.2.3 Step three (a): Relating the meaning units

Through the process of reflection the researcher re-grouped the meaning units/categories based on emerging themes. The related classifications were identified in the previous step, that is, step two, with numbers and the meanings are bracketed.

3.9.2.4 Step three (b): Reflecting on the meaning units and extrapolating the essence of the experience for each subject.

The researcher reflected on participant's expressions with an emphasis on the phenomenon being investigated, in this case the nurse's experiences of caring for terminally ill patients with AIDS. This process required reflection and imagination. Transformations were necessary because participants' descriptions reflected multiple realities (Giorgi 1985). The explanations given were based on the essence of every meaning unit and the transformations were presented in a clear manner retaining the participants' descriptions. An example of a meaning unit found in the participants' extracts is illustrated below:

The participants' understanding of caring was expressed as a concept that is intrinsically aligned to nursing. They maintained that it was essential for all nurses to care as the patients surrender their entire lives to them:

“... well I believe that caring is essential in nursing. I think that, that really is the basis of caring...” (Participant 10).

“The patients surrender themselves completely to the hands of the nurse, body and spirit,” (Participant 1).

Some participants did mention that there are some nurses whose focus is mainly on earning money, and not on the essence of caring as has been stated above. They believed that such an extrinsic focus results only in an unfulfilled life, as one said:

“...if you take nursing as a job, you have lost it as you are not going to be happy even yourself, because whatever, you do, you do not get satisfied.... If you just need money, money, money, you have lost the concept of caring,” (Participant 9).

3.9.2.5 Step four: Transformation of the subjects’ everyday expressions into psychological language

Through a process of reflection and imagination, the researcher transformed the subjects’ everyday expressions into psychological language, with an emphasis on the phenomenon being investigated, that is the participants’ experiences of caring for terminally ill patients living with AIDS. The transformed meaning units were then classified into themes (Refer chapter 4) which were further divided into sub-themes according to the research questions used in the study as shown below (Refer Table 3.4).

Table 3.4: Categories, themes and sub-themes

No.	Categories	Theme	Sub-Theme
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1.	Conceptualization of core terms: caring and terminal illness	1. Caring 2. Terminal Illness	<ul style="list-style-type: none"> • Caring as a Personal Value System • Caring stems from one's background • Caring is transforming • Caring requires sacrifice • Caring is holistic • Terminal illness requires long-term care • Terminal illness requires care to ensure patients have a peaceful and dignified death. • Terminal illness is an opportunity for new learning • Terminal illness raises consciousness on HIV/AIDS
2.	Care Experiences in the context of caring for terminally ill patients with AIDS	1. Social Networking Systems 2. Hindrances to care of AIDS terminally ill. 3. Mechanisms of adjusting in palliative care.	<ul style="list-style-type: none"> • Mutual Support • Overwhelming effects of AIDS • Fear of infection • Imbalances in the health care system • HIV/AIDS described as "just another common condition" • Antecedents that alter a person's level of caring • Caring conflicting with the need for money • Accepting death as reality of life

3.9.2.7 Step five: Synthesis of transformed meaning units into a consistent statement of the structure of learning

Through synthesizing and integration of the emerged meanings, the insights gained in the previous steps were formalized into a consistent structure supported by the empirical studies (Refer Chapter 5).

3.10 TRUSTWORTHINESS OF THE RESEARCH

A number of strategies were used to enhance the validity of the study. According to Lincoln and Guba (1985), trustworthiness in qualitative research is assessed by using the principles of sound credibility in the sense that the findings of the study can be believed as true. Confirmability is the assurance that the research findings reflect the ideas of the participants (objectivity), not the researcher's biases and dependability. It also means that if the individual in-depth interviews and cues are used at different times in similar settings, they would give similar results to the findings of this study, implying that the findings can be applied or transferred to other similar contexts.

These concepts were applied during the study as follows:

3.10.1 Credibility

In this study, the researcher gave a short summary to the participants after each individual interview to check that their ideas had been properly captured and to provide an opportunity for correction or clarity where necessary. In addition, credibility or truthfulness was ensured through:

- Audio-recorded interviews to ensure that the researcher did not misinterpret the participants' own wording.
- Field notes written directly after each interview to ensure that no meaningful information was lost or forgotten.
- Reporting the participant's own wording to demonstrate the diversity of their responses and ideas about the phenomena under study.
- Continuing with data collection until data saturation was reached.
- Analyzing and discussing responses with colleague in order to make sure that the participants' opinions were reflected (triangulation).

- Consulting with the research supervisor to ensure that the processes and findings were reviewed.
- Comparing the findings of the current study with published studies and other literature, (triangulation).
- Seeking experts' knowledge, such as asking a skilled phenomenologist for guidance through the data analysis process.

These steps outlined above ensured that the aspects of member checking, data triangulation, (reference to the multiple sources), peer debriefing and reflexivity were considered.

3.10.2 Confirmability

Confirmability or objectivity of this study was established through several techniques. To observe bracketing, the researcher kept disclosed her ideas and experiences in writing as an awareness of personal opinions and beliefs on the care of patients dying from HIV/AIDS so that they did not influence the study. Field notes were also written during and after each interview to ensure that the participants lived experiences were recorded accurately from their perspectives. An audit trail, which is a '*systematic documentation of material that allows conclusions to be drawn about the trustworthiness of data,*' (Polit and Beck, 2006:495), was established by clarifying the steps taken in the research process in order to ensure that the philosophical underpinnings of the study were adhered to. Participants were also contacted in cases whereby clarity was needed on unclear concepts.

3.10.3 Dependability

The researcher linked the findings of this study with other evidence-based scientific findings. Also, a proposal regarding the subject was presented to a panel of experts

at the University before the data collection process to check whether they felt the process of research was appropriate to answer the research question. Broad questions that have been used successfully as data collection tools in other contexts were adopted for use in this study. For example, the interview guide has been adopted from De Villiers and Ndou, (2008). (Refer Appendix Two on page 145).

3.10.4 Transferability

The phenomena under study were described in detail to allow readers to evaluate the contexts where the conclusions of the research can be relevant. In qualitative studies, adherence to philosophical underpinnings and engagement in a thorough process of data collection ensures trustworthiness, as opposed to objectivity and rigid adherence to research designs in quantitative studies (Burns and Grove, 1995). Accordingly, transferability was achieved through rich description, whereby the research process, the characteristics of the participants and the study context are supplied to allow readers to determine to what extent the circumstances are similar to their own context. A process of purposive sampling was adopted for the study based on the researcher's personal judgment of staff members who would be informative on palliative care.

3.11 ETHICAL CONSIDERATIONS

Formal ethical approval was obtained from the University of KwaZulu-Natal Humanities and Social Sciences Ethical Committee, and gatekeeper permission was obtained from the management of the hospital to ensure that the rights of the participants were protected. An information document was given to all participants and their written consent to participate in the study was obtained. To protect the rights of the participants the following steps were taken:

- The information document was given to all selected participants and the researcher carefully explained the nature of the research, the goal and the methodology of the research steps (Refer Appendix One on page 142). Participants were given about 10-15 minutes to read the document and sign the informed consent.
- Information on their right to refuse to participate or withdraw from the study without repercussion was reinforced in the information document.
- Data gathering was limited to eliciting information that was relevant to the study by means of face to face interviews and the use of probing questions.
- During the interviews, the ground rules were verbalized. Where appropriate, sessions were ended with a debriefing session, particularly where emotionally challenging issues had surfaced during the interviews. If deemed necessary, participants were referred to a medical doctor, social worker or one of the hospital counselors.

3.11.1 The choice to participate

Although participants were invited to participate in the study, participation was voluntary and all respondents had the right to withdraw at any time without fear of repercussion. In addition, at the time of data collection, the researcher was a lecturer at an independent nursing college, thus had no dealings with the employees of the hospital.

3.11.2 Anonymity and confidentiality:

Participants were assured that there would not be any link to their identification during data collection, data analysis and dissemination of findings. By asking them to

choose a pseudonym, the questionnaires were anonymous and could not be traced back to them. Anonymity was also maintained by sometimes referring to them by number, (Participant 1, 2, 3, etc.) The information obtained from the respondents was kept as confidential as possible by storing all data in a locked cupboard to which only the researcher had access before and during data analysis.

3.11.3 Risks

Participants were assured there was no risk attached to the research and that they would not be harmed in any way. The nature of the study was explained to them and they were assured that they were at liberty to ask any questions if clarification was needed.

3.11.4 Benefits

The participants can benefit from the study by making use of the results to change their practice. The findings of this study may also help relevant authorities to gain information that may be utilized when making policies relating to palliative care, thus enhancing the quality of nursing in palliative care. As the study's results will be presented to the hospital management, and at relevant conferences of HIV/AIDS and published in journals its benefits will be widely disseminated.

3.12 DATA MANAGEMENT, STORAGE AND DISPOSAL

Before and during data analysis, the transcripts were kept in a locked cupboard to which only the researcher had access. Data was captured on a computer secured with a password known only to the researcher, after five years it will be deleted permanently and hard copies kept by the supervisor. Audio tapes were kept in locked cupboards which could only be accessed by the researcher. The information will be destroyed by burning after a period of five years.

3.13 CONCLUSION

This study was based on a constructive paradigm and made use of phenomenological enquiry as it sought to describe and understand the participants' definition of their lived situations/experiences. The use of the phenomenological approach facilitated greater understanding of the nurses' perceptions and meaning of their situation of being confronted with the suffering and death of AIDS patients. The information obtained may assist the hospital under study and other similar settings to improve management systems to ensure quality improvement strategies for the staff, the patients and their significant others in palliative care settings.

The results of the study are presented in chapter four.

CHAPTER FOUR

PRESENTATION OF THE RESULTS OF THE STUDY

4.1 INTRODUCTION

This chapter will present the main findings of the study. As stated in previous chapters, individual in-depth interviews were conducted among the nurses with the aim of exploring the meanings they attached to the concepts of caring and terminal illness and also exploring their lived experiences in the context of caring for terminal HIV/AIDS patients in the palliative wards. Giorgi's (1985) steps of data analysis aligned to Husserlian Phenomenology were used to make sense of the data. The process of Giorgi's five steps was described and presented in chapter three. This chapter will present the themes and subthemes that emerged from the data analysis process aligned to the concepts of caring; terminal illness; and the lived-experiences of the nurses in terms of caring for terminally ill patients with AIDS.

4.2 RESEARCH FINDINGS ACCORDING TO CATEGORIES, THEMES AND SUB-THEMES

4.2.1 CATEGORY 1: CONCEPTUALIZATION OF THE CORE TERMS: CARING AND TERMINAL ILLNESS

4.2.1.1 THEME 1: CONCEPTUALIZING CARING

According to the findings of the study, five attributes described the psycho-social range of meanings that participants attached to the concept of caring. Nurses described caring as (1) a personal value system; (2) stemming from one's background; (3) transforming; (4) requiring sacrifice; and (5) holistic. These attributes will be unpacked and discussed further in the following sections.

Sub-theme 1.1: Caring as a personal value system

Evident from the data analysis, participants conceptualized caring as a cardinal aspect in nursing. The concept of caring was characterized as an attribute or a mechanism that enabled the nurses to provide quality of care and improve the well-being of others. It was also noted from the participants excerpts, as illustrated below, that caring was an essential trait in the nursing profession. Moreover, caring and their desire to help others was also regarded a catalyst in enabling the participants to continue working within the context of palliative care. The selected excerpts below highlight this further.

“I like the profession, I really like it and I talk about something I love, that is, caring,” (Participant 1).

“I like caring for patients, there was a time when I have actually, tried to run away from the caring profession, by doing a different job but here I am, I am back again. I got drawn back to it, I like caring for patients, I truly, do,” (Participant 9).

“I believe that caring is essential in nursing. I like caring for the sick so much that I would like to see more people trained in nursing,” (Participant 4).

“Nursing is really a call, this is what I have come to believe, so when they {nurses} care basically they fulfill their calling when they show caring,” (Participant 2).

Sub-theme 1.2: Caring stems from one’s background

Emerging from the data, participants expressed that their values regarding caring in a sometimes overburdened environment of palliative care in the context of HIV/AIDS had been shaped by having had previous exposure to episodes of caring for family members who had been ill and in need palliative care. Some participants also explained that they had learnt about caring from family members who were nurses who had displayed values of compassion, empathy and caring and that their example

had shaped their own meaning of what caring means. The selected excerpts presented below highlight this further.

“My own background helped me a lot. I come from a caring family and the marvelous role models I had when I was on training. They were totally professional people and they displayed compassion and dedication,” (Participant 10).

“Caring for me started from home with my mother who was sick in 2003. When I helped her, it’s easier to help someone who is not your relative,” (Participant 2).

“My whole experience of caring started from home before I actually did any training. When, I was young, I cared for my sister who was sick. I used to take care of her, when I came from school. When I came here, {hospital} it was then channeled to the right place. My approach to caring, is to see all patients as my sister or brother, or mother/father,” (Participant 4).

Sub-theme 1.3: Caring is transforming

Results showed that participants perceived caring as transforming in that they regarded their role in caring as a way of changing the lives of their patients as they helped them to manage their illnesses. It was evident from the data, that caring was seen as a process of renewing hope and enriching the lives of the patients. Nurses stated that encouraging adherence to antiretroviral medication and encouraging acceptance of HIV diagnosis were ways of caring. Participants understood their role as being agents of change in the way they care for people living with HIV/AIDS and help them by turning a negative experience into something that encourages positive living and improved health outcomes. The excerpts presented below are examples of this shared meaning.

“For me I get joy when I help or care for someone, and I notice improvement, that the patients manage to do something for themselves” (Participant 9).

“As a nurse, I feel great when a patient is discharged home, and after diagnosis with HIV/AIDS, I give them hope through adherence to treatment,” (Participant 3).

“I feel very good when I help them {patient} and want to do more,” (Participant 6).

Sub-theme 1.4: Caring requires sacrifice

It emerged from the data that participants characterized caring with sacrifices of time and even money. They noted that caring in the context of palliative care is a challenging aspect of a nursing career as the nature of taking care of terminal patients suffering from HIV/AIDS means that they are sometimes compelled to make many sacrifices. Reflected in the data, such sacrifices included both time and money in that participants often worked extra shifts and longer hours and by continuing to work in the palliative wards sometime sacrificed more lucrative positions in other wards. Sacrifices were also noted in terms of spiritual and ethical values, whereby participants expressed that as nurses, they had to be professional and unbiased and sometimes had to sacrifice their own value systems and beliefs in respecting the needs of the patient and offering holistic care to for the ill and dying. The excerpts below reflect this further.

“Sacrificing your time for another person, {patient}, as well as yourself to another emotionally, spiritually, ethically,” (Participant 4).

“Caring for me, in essence means to be everything for the patient in need, to be the mind and think for the patient, be the feet to walk for the patient, and the mouth, or the voice of the patient,” (Participant 2).

“Many a times caring is about make sacrifices. We sacrifice a lot, our meal times, family times in order to save and bring relief to the lives of the ill people, dying of AIDS,” (Participant 9).

“When I am by my patients, I do it with my whole heart. I tend to forget other people when I am next to my patients,” (Participant 4).

“We are nurses 24 hours around the clock. This is what I always tell my nurses. In the olden days, this was very clear in that even when one was officially off duty, we were simply called, “come back on duty and work, when there was the need” without being paid, hence we stayed with our uniforms ready, even on days off, because we never knew, when we would be called,” (Participant 1).

Sub-theme 1.5: Caring is holistic

Affirming the interrelationships of the bio-psychosocial and spiritual dimensions of people, the nurses stated that they embraced a holistic approach and cared for terminally ill patients as human beings with bodies, minds, souls and spirits. Furthermore, owing to the fact that HIV/AIDS is a debilitating disease that threatens the lives of patients, their assessments and interventions are integrated within a multi-disciplinary team of health care workers who attend to the needs of the patients. The statements below express this further.

“I feel it is the holistic care that one renders for the patients, not only, to terminal ill, but all patients who have a sick role,” (Participant 2).

“Taking care of patients, emotionally, socially, care for everything, ekuyena, neseduze kwakhe {that is, what the patient has including what is in their surrounding},” (Participant 6).

“Caring includes the whole person, meaning to give love to the unloved; the physically challenged, to bath and feed them etc; to the socially isolated, to maintain communication with the patient freely, so that patients are not afraid to approach you; psychologically, to respect them as human beings and individuals,” (Participant 8).

“Due to HIV/AIDS caring now is more holistic than ever. Because you need the multi-disciplinary team to be involved, e.g. the social worker for those patients with social or financial problems; counselors to support for HCT {HIV Counseling and Testing} for treatment adherence; spiritually they are drained; physically they are demanding, {in the sense that they lie for too long in bed},” (Participant 1).

“Caring for terminally ill with AIDS, yeah it is demanding, because we have to deal with them {patients}, deal with ourselves and our relatives who are chronically ill and bedridden at homes, what we do for them {patients} we have to carry on with our own, knowing that there is no cure,” (Participant 7).

The second theme stems from the way in which nurses perceive the concept of terminal illness and this is discussed below with its four sub-themes.

4.2.1.2 THEME 2: CONCEPTUALIZING TERMINAL ILLNESS

The data revealed terminal illness was conceptualized by the participants as having the following four attributes: (1) requires long-term care; (2) patients are entitled to a peaceful, dignified death; (3) an opportunity for new learning; and (4) raising consciousness on HIV/AIDS. The cognitive and practical meanings of these attributes reflect how nurses perceive their role in preserving the quality of life of patients who are terminally ill with AIDS whose illnesses are no longer responsive to curative treatment. These will be discussed further below.

Sub-theme 2.1: Terminal illness requires long-term care

Recognizing the impact of antiretroviral drugs which significantly delay the progression of HIV to AIDS, the participants affirmed that people living with AIDS can live relatively normal, healthy lives, particularly in cases where early access to treatment and adherence thereto is fostered.

Evident from the data, terminal illness in the context of HIV/AIDS and caring thereof was characterized as something long term and sustained either through home care or in-hospital care. As AIDS is a multi-system disease, it was explained by the participants that their physical needs can vary and the nurses face the challenges of trying to meet the needs of terminally ill patients who suffer symptoms of total body

pain and inability to express themselves. In order to meet the physical needs of the terminally ill patients, prolonged and time-consuming nursing care such as feeding through nasogastric tube feeding and total care of the unconscious patient is required. Thus participants referred to patients that have a terminal illness due to AIDS as those requiring long-term care, particularly if they are sustained on continuous treatment such as antiretroviral drugs which may enable them to live longer than when they are not taking the treatment. The excerpts below reflect this further.

“All the patients with terminal diseases have incurable diseases, e.g. DM {Diabetes Mellitus}, HPT {Hypertension}, CVA {Cerebro-Vascular Accident}, HIV/AIDS patients. All such patients need special care, and can be taken care of at home or in hospital. At times they are independent enough for self-care in their own communities e.g. IDDM {Insulin Dependent Diabetes Mellitus} patients,” (Participant 6).

“Terminal patients are sick, and may have a disease that has no cure to carry for the rest of their lives. It does not mean that they are dying. They may live for a long time. Okay, only those who are taking Anti-retroviral Drugs, you find that they live longer,” (Participant 7).

Some patients are admitted with opportunistic infections due to AIDs, such as meningitis and they cannot verbalize pain, or may be unconscious requiring nasogastric feeding and total nursing care, ending up spending a lot of time with one patient, (Participant 2).

“I like to give my patients love: physically by bathing or feeding them etc, socially, by maintaining communication with the patient freely, so that patients are not afraid to approach you, psychologically, respect them as human beings and give on-going counseling on their ART treatment regimens to keep them motivated to comply always, even at homes, (Participant 4).

Sub-theme 2.2: Terminal illness requires care to ensure patients have a peaceful and dignified death

Although palliative care was affirmed by the participants in the previous sub-theme as improving patients' quality of life; their statements also reflected that they maintained a realistic stance towards death and perceived terminal patients as

having reached a stage where death was inevitable. They were of the opinion that “*nothing could be done for terminal patients*” as they would not respond to curative treatment. They believed that the dying process needed to be regarded as an acceptable normal process and that it was their role to care for dying patients and help them to die peacefully and with dignity. This sentiment is illustrated in the statements below:

“Terminal patient is a dying patient, someone who is about to die, they are very ill and dependent for all their needs. They are at the stage where they are about to die,” (Participant 8).

“The patient who is terminally ill; it is hard for them to recover. Nothing much can be done really. Therefore, it means that I should help them to die with dignity and give them the treatment that is due for pain control, so as to die peacefully,” (Participant 2).

“Nothing much can be done for terminal patients, the only thing is to assist in pain control,” (Participant 10).

Sub-theme 2.3: Terminal illness is an opportunity for new learning

The participants acknowledged that their behaviors have been modified or changed through the knowledge and skills gained while caring for suffering, dying patients who have AIDS. In addition, the participants were able to transfer the knowledge gained while nursing these patients with AIDS to their own family members who presented similar symptoms to the patients they nursed. The quotes below illustrate this sentiment:

“Actually, there are also opportunities that HIV/AIDS has provided; we had chances to attend bereavement courses. It was very helpful, because we also have deaths at home as well. This helps us to counter act the feeling of sadness we feel each time we send a patient to the mortuary, or bury someone. We are well equipped now. Every department is also provided with a counselor, all you need is to make an appointment and get the help to share your feelings. Earlier on in nursing, we did not have such opportunities,” (Participant 1).

“I have learnt a lot about AIDS patients. It has many opportunistic infections, which makes me refer back to my own family, to my family members who once had unusual illness and perhaps died, I am able to relate and associate patients’ illness with some conditions in my family. This helps with diagnosis of my own family,” (Participant 7).

Sub-theme 2.4: Terminal illness raises consciousness on HIV/AIDS

Responding to the reality of death faced by terminal patients with AIDS, participants were awakened to the reality of their own mortality. With the HIV/AIDS epidemic reaching such proportions and dealing with suffering and death on a daily basis made participants realize that they, too, might suffer in such a way one day and would appreciate kindness and care. This motivated them to be more thoughtful about their actions and render quality care, that is conscientious and loving that will preserve the dignity of their dying patients. This is expressed in the following utterances by the participants:

“Caring for terminal patient helps me, because it gives me the awareness that, one day, I will be in their state as well, so this awareness, helps me to care for others more, knowing that I will be there one day,” (Participant 1).

“If you put yourself in their (terminal patients) shoes you will know that someday, it could be you, or anyone who is very close to you. It’s things like these you need to remember when you are still alive so as to care for patients with dignity,” (Participant 7).

*“At times I think about death, I ask myself, if it were me, what would I do? Each time, in the evening, I reflect on this question. Sometimes, I think, I will be able to do 1,2,3,4 but, “huh”, you don’t know in reality. I do what I would like done to me.
So I care for my patients so they can feel cared for and loved. Eye for an eye, if I do good, some body, will do good for me one day,” (Participant 6).*

The second category discusses the experiences of caring in the context of a palliative care setting.

4.2.2 CATEGORY 2: EXPERIENCES OF CARING IN THE CONTEXT OF PALLIATIVE CARE

Three themes consistently emerged from the data analysis as compelling forces that influenced the nurses' actions, behaviors and opinions as participants described their experiences of taking care of terminally ill patients who suffered from AIDS. These were conceptualized as: (1) the social networking system; (2) factors that hinder the provision of quality care to terminally ill patients; and (3) the mechanisms of adjusting to terminal care. These themes had various sub-themes which will be discussed in the sections below.

4.2.2.1 THEME 1: THE SOCIAL NETWORKING SYSTEM

Being aware that the nature of caring for terminally ill patients requires the interventions of a variety of health practitioners, participants explained that their inter-dependent roles resulted in a state of affinity with other members of staff, which, in turn, developed into collegial relationships and wider social networks. In the context of providing palliative care and managing their care-giving roles efficiently, participants admitted that they drew upon the support of their colleagues and thus developed friendship systems among them. They described how they helped each other by offering a "helping hand" or "support", the "close bond/relations between staff" and the co-operation they received from their own colleagues and health workers in other disciplines. The participants also noted that such supportive activities of togetherness enhanced collaboration and uplifted the demands of caring for terminally ill patients who had high dependency needs due to the complexity of AIDS. This enabled them to provide the utmost care with undue stress. This sentiment is illustrated in the statements below:

“We sometimes talk with my staff, among ourselves, sharing experiences of the day, our challenges and the things that made us happy in the day. At times the ward doctors, especially the female doctors join us in these social gatherings. This helps to ease the tensions or conflicts we meet in our work-place,” (Participant 3).

Harmonious relationships make work easier for me. Even when there are challenges in the ward, where more patients die, but if there is team work to help each other and healthy close relationships in the environment, we cope better, (Participant 6).

As the participants discussed their experiences, it became evident that mutual respect had a large part to play in the theme of social networking. It was thus placed into a sub-theme to highlight the way in which many of the social networks were founded on mutual support and collaboration.

Sub-theme 1.1: Mutual Support

As the interdisciplinary and the multi-disciplinary team (MDT) approach to care is applied to the delivery of palliative care, the nurses are familiar with collaborating with other teams to the challenges of terminal illnesses and death. Multi-disciplinary teams function as supportive structures that enhance work flow, create harmony and help staff members let off built-up tensions to each other, all of which contribute towards the well-being of the terminally ill. One of the senior participants with over 20 years of experience in the care of terminally ill patients recalled fondly the great times when teams felt comfortable enough with each other to provide and obtain help when needed. However, participants explained that the supportive working relationships between the team members are currently sometimes lacking as a result of staff shortages, as they now have to put more focus on their tasks and don't have as much time for collaboration. In spite of the perceived organizational challenges, the value of the MDTs was described further as contributing to personal growth as it

provided opportunities to for nurses to exchange their knowledge and skills to maintain patient focus. The following abstracts exemplify collaboration:

“We all supported one another and helped one another, sometimes if you saw something which was too much for one, we all came around and helped. The one sister would just call and ask for assistance, please come and help, I have a problem here, and we would respond. The team work was absolutely wonderful, but with the rush in our work or low staffing levels, we often miss this opportunity,” (Participant 10).

“Team work is uplifting; if you ask someone to do something for a patient, and the work is shared, you find that the work is easier and when we share in our diversity in terms of knowledge and skills we learn from one another, and are re-inforced too,” (Participant 7).

“There are many, many terminally ill patients we nurse, mainly with HIV/AIDS, a few cancer cases and other chronic disease such hypertension and Diabetes Mellitus, but because of teamwork, support from colleagues and other support staff, we manage well. At times we can joke and laugh at funny things in the ward, this helps to relieve our stress, (Participant 9).

The second theme that was identified as participants discussed their experiences of caring for terminal patients related to the factors that hinder the provision of quality care in the context of palliative care.

4.2.2.2 THEME 2: FACTORS THAT HINDER THE PROVISION OF QUALITY CARE IN THE CONTEXT OF PALLIATIVE CARE

It emerged from the data analysis that there were multiple barriers that impeded or hindered the nurses’ abilities to provide quality palliative care for the terminally ill patients with AIDS. Six sub-themes emerged which included: (1) the overwhelming effects of AIDS; (2) fear of infection; (3) imbalances in the health care system; (4) HIV/AIDS being described “as just another common condition”; 5. antecedents that alter levels of caring; and (6) caring conflicting with the need for money. These are discussed further below.

Sub-theme 2.1: The overwhelming effects of AIDS

It became evident that because of the overwhelming nature of the disease, from the psycho-social responses to the chronic illness trajectory, the nurses confirmed that they did not always cope effectively in their roles as carers. They explained that they experienced periods of intense emotions at various levels which affected their spiritual, emotional and physical well-being and led to maladaptive coping. They described the impact of caring for terminally ill patients with AIDS as an overwhelming experience as they often felt frustrated from being the recipients of problems from patients and their relatives while they have no one to confide in. Nurses described feeling “drained” and that terminal care “demands a lot” on the part of the nurses, and sometimes they felt unable to cope well in their job due to exhaustion. This is confirmed in their statement below:

“Spiritually the nurses are overwhelmed and drained; physically too, Ja, the disease is very demanding in the sense that patients lie for long in bed, and we have to give total blanket bath, feeding & listen to complaining visitors....” (Participant 6).

“At times you find that you have problems with admitted as well as discharged patients who have no one or have no money to go home. You find that as a nurse you are exhausted not because of the work but because of the emotional things you carry,” (Participant 3).

“We deal with a number of dying patients, for example you find that there are at least two or three deaths a day,” (Participant 7).

“We find that as nurses we carry the pain alone, as the relatives and patients have off-loaded on us to relieve their pain. The end result of this is that we are helpless, and angry, as we can’t go beyond your capacity, with no one to share the pain with, as a result some simply absent themselves” (Participant 9).

In spite of the above statements, however, the findings showed that participants were imbued with the goal of achieving the best quality of care for the terminal patients in the context of palliative care. During the discussions it became clear that some

nurses did all they could to help their patients and give them a better quality of life not only by caring for them, but also by educating them about AIDS so as to assist their recovery. This is illustrated in the abstract as follows:

“I so wish to engage more with patients, spend time with them, listening to them and helping them where I can, but there is too much paper work, than patient care,” (Participant 1).

“It’s painful and mind-blowing for me. Sometimes I ask God, with a sense of guilt, “why,” especially, if someone of my age dies, I often feel like telling everybody, that AIDS is still alive, so that they can be aware that people are dying of AIDS, but due to shortage of staff we are restricted to do more, (Participant 3).

Sub-theme 2.2: Fear of infection

Based on the fact that HIV infection and AIDS carry a burden of fear for the carers; the data revealed that the nurses utilized reasonable precautions, such as the wearing of gloves or masks when handling the terminal patients under their care in order to minimize the risks of contracting HIV or other debilitating diseases such as TB. However, the nurses stated some aggravating circumstances that exposed them to the risk of infection. These were mainly related to the patients’ attitudes, as those who were in denial of the diseases became offended when precautionary measures were utilized. In other situations, the nurses advised the patients to use protective measures when coughing in order to reduce the risk of transmission of the disease and their non-compliance made the nurses reluctant to go into the wards to care for them. Their fears were based on the reality of the diseases South Africa is battling with. Apart from HIV/AIDS, they could also be exposed to other virulent diseases such as Swine Flu and the extremely drug resistant TB, although cases of the latter have not yet been diagnosed in the institution under study. The statements below are expressive of this theme:

"It's hard going to the wards, with the fear of getting TB {Tuberculosis} and or worse still, HIV/AIDS from the patients. This is a real challenge," (Participant 4).

"Most of the patients are in denial of their HIV/AIDS status, there are few who accept what they are. There are some who accept it when you use gloves when caring for them, but others feel offended. I remember there was a patient in OPD, when I told him to close his mouth when coughing, he was angry because he told me "waze wangiphoxa", {you are making me feel belittled}." (Participant 2).

"Coming here for training, I feared TB, XDR, HIV Transmission, Swine Flu etc...you end up not caring effectively or sufficiently for the patients due to fear of the contracting the disease," (Participant 5).

"The suggested HIV Test came out positive...we were shocked because we cared for the patient without gloves," (Participant 1).

Sub-theme 2.3: Imbalances in the health care system

Recognizing the strategic and the global issues in the context of palliative care, the nurses expressed concerns on issues that impinged on the delivery of palliative care services. Attention was given to their negative feedback that was related to professional standards and institutional resources in terms of human resources and equipment. The nurses were concerned that the professional standards had dropped as a result of staff shortages and lack of equipment. Evidence from the data sources revealed that when reflecting on the strategic and global issues the nurses believed that all the terminally ill patients who are in need of palliative care services might not receive appropriate care under the current restrictions. One of the major issues that came out from some participants was the use of locums or sessional employees, who are called in for a specified period (a day or a month) to cover the organizational operations in the absence of permanent employees who might be away due to sickness or simply not at work for unforeseen reasons. Because the locums often come in for a day only, at times without proper orientation, the participants described

them as people who, because they may not be familiar with the institutional protocols or procedures, may fail to comply with the required or expected work routines, thus upsetting the existing and acceptable levels of work performance. It was suggested by the participants that in order to maintain the organizational system and continue to render quality care of terminally ill patients, some systems need to be put in place. For example, managers themselves need to do their supervisory duties, such as counseling and listen to staff problems and managing employees by providing the necessary tools such as adequate staffing and equipment to enable the nurses to carry on delivering quality care to the terminally ill patients. The statements below confirm this:

“At times, I ask myself about the standards of nursing, “What’s going on? Are the standards dropping when there are so many deaths in increasing numbers? Are we doing something wrong?” (Participant 3).

“We cannot give the best quality care we could with shortage of staff; we can only manage the basics. But at times our patients need more than just this, they need individualized care,” (Participant 8).

“We need to have more permanent staff. We need to improve doctors too, to have one doctor for the floor with 44 patients is difficult,” It is not good to depend on locums; they come and mess up your ward and systems and go away. We need permanent staff to maintain our systems, (Participant 7).

“We need supportive managers. It is important to listen and encourage staff to cough up, their problems...He or she cannot give care very well for patients if she has bottled anger or issues....”they should also manage absenteeism and time-keeping for tea and lunch breaks and punctuality, for smooth –running of the wards,(Participant 9).

“We need resources to be able to work effectively. Equipments help us to care better...” (Participant 7).

“We have lost patients unnecessarily through faulty equipments,” (Participant 6).

Sub-theme 2.4: HIV/ AIDS described as “just another common condition”

Because people with AIDS have opportunistic infections, such as Tuberculosis and Pneumonia, the nurses explained that these infections were so common among the terminally ill patients they cared for that they perceived them as being synonymous to HIV/AIDS. Furthermore, because most of the cases they were dealing with on a daily basis were AIDS related, the participants felt that caring for terminal patients with AIDS was “self-limiting and monotonous” as they did not have the opportunity learn about new diseases and current treatments and procedures. They felt that the monotony of continually caring for patients suffering from the same conditions might have an effect on the quality care they provide and also that their academic progress and growth was somehow restricted. This sentiment is illustrated in the quotes below:

“As nurses on training, it is really, a challenge. Because the cases you care for are all categorized under the same conditions HIV/AIDS; this is limiting in the sense that you do not get to see other conditions, as they are mostly, having HIV/AIDS as the underlying cause...e.g. cases for TB, Pneumonia You want to see different conditions, in-order to be exposed to learning. Basically, in the clinical practice, it’s like you are dealing with HIV/AIDS and TB only,” (Participant 2).

“Caring for HIV/AIDS Patients is not stimulating. Because we see the same diseases and we always give the same treatment as they {patients} are mostly, having HIV/AIDS, it is very rare to find different diseases,” (Participant 5).

Sub-theme 2.5: Antecedents that alter a person’s level of caring

It emerged from the findings that participants’ experiences in palliative care were perceived in relation to their personal circumstances and value systems. During the interviews it became evident that some participants’ personal experiences of abuse, violence and even being infected or affected by HIV/AIDS could have an effect on their nursing practices and the level of care they provided. Thus, when a nurse is

placed into a palliative care setting, their personal circumstances and history should be taken into account in order to provide appropriate support to enable them to function at the best possible level. Examples of antecedents were reflected by one participant's excerpt:

"We also need to remember the background from which some of the nurses come from, before we judge them. Some came from a past of violence such as the apartheid, others have lost both parents, so this is the work force we have and may thus not care much about the pain of a patient. These children grew up without a background of feeling loved and cared for," we need to support them (Participant 9).

Sub-theme 2.6: Caring conflicting with the need for money

When the question of money or salary was discussed at the interviews, it seemed that the participants had some mixed feelings. While affirming the need to be paid for their jobs as carers, the participants expressed that there were more important issues than money and that nursing was more of a vocation than a job. They accepted that they needed a salary to live, but that the care they provided was more important than receiving a bigger wage. They expressed disapproval of those nurses who worked purely for a salary, saying that they were uncaring of the patients' needs and were more focused on getting their monthly paycheck than the recovery of those in their care. The statements below highlight this sentiment:

"It is not about working for money, yes, a nurse needs it for living, but it's about giving your whole heart to the patients," (Participant 2).

"Yes, money is important, but it is not everything. I value caring for my patients above everything; if they are happy, I am happy too," (Participant 9).

"If you take nursing as a job, you have lost it as you are not going to be happy even yourself, because whatever, you do, you do not get

satisfied. If you just need money, money, money, you have lost the concept of caring,” (Participant 1).

The third theme discusses the mechanisms used by nurses to adjust to caring for terminal patients in palliative care contexts and includes a sub-theme as illustrated below.

4.2.2.3 THEME 3: MECHANISMS OF ADJUSTING WHILE CARING FOR TERMINALLY ILL PATIENTS WITH AIDS.

The participants admitted that as carers in the context of caring for HIV/AIDS patients, they often experienced emotional and stressful situations which made them feel vulnerable and threatened, thus placing their emotional, spiritual and professional well-being at risk,. However, through their prolonged exposure to the care of terminally ill patients with AIDS, they had learnt some mechanisms, both internal and external, that had assisted them to cope with the stress they encountered daily in their lives as carers of dying patients and regain their emotional status quo/state of equilibrium. The findings showed that nurses relied on internal mechanisms such as love, religion and the application of the “Golden Rule” principle of reciprocity that one should treat others as one would like to be treated, as well as external mechanisms such as counseling and support from senior staff. The excerpts below illustrate some of these:

“And if you adopt a picture that every person you look at is the image/picture of Jesus Christ you can never go wrong or make a mistake, you will care right through,” Participants 2)

“Love, keeps me going on to give the care I can to the best of my ability, and keeps me passionate about my job, to actually want get up and go to my work. This is sustained with prayer, when, I wake up, I always ask God, “give me strength to carry through this day,” (Participant 3).

“...because it’s so hard to care for dying patients, what gave me the motivation to help them{patients} was to see the person as Christ Himself, or Ali or Shembe as lying there, needing me to care for

Him... When you do so with your own strength, you cannot..."
(Participant 1).

As way of coping with the challenges of caring, I do what I would like done to me. So I care for my patients so they can feel cared for and loved. Eye for an eye, if I do good, some body, will do good for me,"
(laughing out loud), (Participant 6).

"...at the end of your nursing experience, you find that you need counseling yourself. We sometimes share with my staff, that it would be very helpful if there would be someone, sorely supporting the staff, so that we can cope with the situation because we are having a lot of experiences that are draining us. Sharing experiences of the day allows for psychological healing," (Participant 3).

"There is a senior manager in my unit who always looks at negative side of things. Even when we have done the best we could, she comes in the unit and finds little and insignificant things that are not done, e.g. one bed that is not made properly, and makes a noise with such, like there is nothing else that was done well in the ward. We would appreciate a, "thank you for the good things we have done". So that we can be motivated to come to work the following day, and not discouraged by criticisms," (Participant 4).

A sub-theme was identified within the theme of coping mechanisms as many of the nurses expanded specifically on how they coped with working with death on a regular basis. This is explained below:

Sub-theme 3.1: Accepting death as a reality of life

As with most other aspects of nursing, the nurse-patient relationship while caring for terminally ill patients is based on good collaboration with the patient. The participants, however, expressed that a good nurse-patient relationship posed difficulties for them as they develop these relationships in the full knowledge that their patients are likely to die. The nurses stated that the clinical conditions of terminally ill patients ultimately worsen and the awareness of death becomes a prominent feature in their lives, forcing them to change their goals and focus on specific end of life goals. This places a huge emotional burden on the nurses who

have become the confidants of their dying patients. It is therefore imperative that they have some kind of coping mechanism to relieve these emotional burdens.

The nurses explained that this necessitated a change of perception (paradigm shift) on their part and that they needed to recognize that death is a reality that is beyond their control, and understand the fact that HIV/ AIDS is a life threatening disease. Some of the participants suggested that they needed to adapt to their circumstances and change their mind sets or perceptions in order to provide hopeful and realistic help to their terminally ill patients. This is illustrated in the abstracts as follows:

“We basically need to adapt to the reality of the situation of HIV/AIDS in-order to help the sick. The disease itself is reality and nothing can be changed as such. It’s me who has to change, and accept that patients with HIV/AIDS eventually have to die,” (Participant 2).

“We need to accept the reality of death, as a daily thing which I cannot change, especially patients who come gasping. Acceptance of the situation, and just to conform to the reality of our time, it’s the only way that helps me out,” (Participant 9).

Some nurses felt that exposure to death and dying provided them with opportunities to discover meaning in life through the lessons they learn from their patients, which helps them to become more spiritual and come to terms with their own mortality. They noted, however, that it sometimes had negative effects, particularly on the younger nurses, whose behaviors demonstrated uncaring attitudes. One of the participants who had in the region of 20 years of experience or more in terminal care discussed the fact that death did not seem to have much impact on the younger nurses, sounding the warning that if they “seem to get used to deaths,” that they would end up being hard and lose respect for their patients. It became evident that

the attitude of “getting used to death” had serious consequences for the nurses as even their colleagues perceived them as failing to grieve over death. Another participant, with three years of experience, made a general comment that staff and relatives have become very blasé and insensitive about death, as seen by giggling, chatting and laughing while laying out the dead. These concerns are outlined in the following observations:

*“The experience of death does not touch them (younger nurses) at all. Even when they are bringing the corpse to the mortuary, they talk something we never did. Exposure to the HIV/AIDS disease as well, makes some hard. They seem to be getting used to death such that it’s perceived as a routine (**Banging with the fist on the table**),”*
(Participant 1).

“Routine death makes the relatives of patients or staff gets used to death; such that they don’t mourn. They take it (death) with the words, “Kade ngafelwa”, {I have long been experiencing losses}, no-wonder some nurses never show any sensitivity towards the dead, they chat, giggle or laugh as they layout, (Participant 9).

4.3 CONCLUSION

This chapter discussed the outcomes of the research findings in depth, integrating the categories, themes and sub-themes that emerged from the data analysis with the actual quotes from the participants as the evidences of their lived experiences. The professionals working in palliative care shared their experiences as they reflected on the factors that hindered and/or promoted quality care within palliative care service delivery. Most of the participants had adopted caring attitudes that were characterized by their willingness to sacrifice their energy, time and money, their willingness to learn from the terminally ill patients and their wish to transform the situations of the terminally ill patients threatened with HIV/AIDS, a debilitating illness, It also became evident that in spite of the difficulties they encountered and the overwhelming burdens sometimes placed upon them, the participants, with the help

of their colleagues, remained resilient and fostered coping strategies that assisted them to deal with the difficulties they encountered as they implemented the principles of palliative care to their dying patients and their relatives throughout its continuum of care, that is, from diagnosis to death and bereavement.

CHAPTER FIVE

DISCUSSION OF THE MAJOR FINDINGS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

This chapter will discuss the main findings of the study which were presented in chapter four. In light of the phenomenological aspect of this study, reviewed literature will be brought into the discussion to position the findings within the global discussions of empirical evidence. The objectives of the study were to explore the nurses' understanding of the concepts of "caring" and "terminal patient", the lived experiences of nurses caring for terminally ill patients living with AIDS and how their experiences influence the care they provide to terminally ill patients.

The findings presented in the previous chapter revealed the lived experiences of nurses who were caring for terminally ill AIDS patients in a palliative care context. This chapter is a discussion of the findings of the study according to the two categories and their associated themes and sub-themes that emerged during the data analysis phase. The two categories are:

- The conceptualization of core terms: caring and terminal illness
- Care experiences in the context of HIV/AIDS

This chapter will also discuss the contributions the current study will make to the body of scientific knowledge and the strengths and limitations of the study. It will present the recommendations and the conclusion.

5.2 THE CONCEPTUALIZATION OF CORE TERMS: CARING AND TERMINAL ILLNESS

According to the findings, the participants conceptualized the terms caring and terminal illness in terms of various attributes. The themes and sub-themes that emerged from the data analysis related to the concepts will be discussed below.

5.2.1 CONCEPTUALIZING CARING

Caring was conceptualized as five attributes that described the characteristics of caring and revealed the psycho-social dimensions of diverse meanings the participants applied to the concept. The sub-themes described caring as: 1) a personal value system; 2) stemming from one's background; 3) transforming; 4) requiring sacrifice; and 5) holistic.

5.2.1.1 Caring as a Personal Value System

Participants described caring as a fundamental and essential attribute in the nursing profession that enabled them to enhance the well-being of terminally ill patients by providing them with quality care and love. Caring and their inclination to care was considered as a drive that kept them interested to continue working in palliative care wards in order to alleviate the suffering caused by AIDS. Nursing was perceived not just as a job by the nurses, but as a calling or mission that enabled them to go beyond the call of duty for the sake of promoting total health and healing for their patients.

Supporting the nurses' conceptualization of caring as a personal value system, Eriksson, (2002) points out that caring, an intrinsic value system, is driven by a caritas motive that is manifested by central values of compassion and human love, which are the basic values that express the art and science of caring. Furthermore,

the author also adds that the motive behind caring is three-fold; to relieve human suffering with love and dignity, to protect from harm and to maintain life and health in a meaningful caring relationship. Similarly, the nurses in the current study had personal values that motivated them to reach out in love to provide palliative care for the terminally ill patients that would provide emotional support and improve their quality of life.

Rytterstroem, Cedersund and Alman (2009:690) who conducted a phenomenological study of lived experiences of nurses working in different environments, argue that "*it is possible to provide care without necessarily caring*", particularly in environments whereby caring is not only disease-focused, but also obstructed by rules and routines that lower the dignity and honor of the patients by treating them merely as biophysical beings. The results revealed, however, that this is not the case with the nurses in the current study, who not only described their profession as a calling, but also demonstrated their commitment to their profession by the love and care they displayed in addressing the psycho-social needs of patients affected with a terminal illness such as AIDS, in order to enhance their quality of life.

The participants demonstrated the true spirit of caring as described by various authors. According to some of these, the values that support and maintain caring include compassion and love, (Eriksson, 2002); consideration and patience, (Rytterstroem et al, 2009); and a culture that values the dignity of human beings, going beyond the call of duty, on a mission to serve for the sake of others by implementing healing environments that promote job satisfaction and retention of carers, as well as total healing of patients in body, soul and spirit, (Eriksson, 2002). These attributes did not only echo the nurses' intrinsic values of love and

compassion as a calling for the suffering and terminally ill patients with AIDS, but also endorsed their interventions in reaching out to relieve the suffering of terminal patients, improve their quality of life and continue to provide quality care in the context of palliative care.

5.2.1.2 Caring stems from one's background

Participants expressed that previous experiences of caring for terminally ill patients with AIDS had shaped the meanings they assigned to the term, care. The caring, dedication and compassion that they had been exposed to by either their family members taking care of sick relatives or by their colleagues in the profession developed their own positive caring attitudes. Tan (2004:7), in a research study describing indoctrination and inculcation of belief systems, upholds a system that introduces a world view or "primary culture," which avoids indoctrination, but promotes intellectual imagination. A culture that promotes critical thinking, as described by the author, allows the developing minds to accept that different beliefs and values exist among people in every society and are essential for survival as a moral community. Furthermore, the author proposes that it is important to guide young minds into thinking patterns that order their own thoughts appropriately, while allowing them to take their own initiatives to action and test their world views accordingly. Likewise, the nurses stated that they had modeled themselves on members of their families or colleagues in the profession who had high standards of caring and professionalism and that this had instilled in them the compassion they needed to take care of patients suffering from AIDS. In addition, many of the nurses had helped in taking care of sick relatives such as their brothers, sisters or parents who were infected with HIV/AIDS which also helped them to carry out their nursing activities with empathy and compassion. The nurses realized that patients need to

maintain their dignity, just as in a family unit, and need to be treated with the respect they deserve, particularly when nursed by junior nurses. Thus, the values of dedication, respect and compassion for the sick were learnt from the nurses' primary sources of socialization, in this case their families and their professional training. These were then internalized and adopted by them as their way of life that guided the way in which they cared for terminally ill patients.

On the other hand, Tan (2004), warns that there can be negative connotations associated with indoctrination of moral values in that it has an authoritarian approach in inculcating belief systems into people which impose fixed rules and dogmatic styles of beliefs that are capable of restricting rather than expanding their intellectual freedom. Nurses work in a multi-cultural environment and need to be aware that in order to remain respectful, different approaches need to be adopted for people of different cultures. For example mature patients from a Zulu background would like the young nurses to address them as "*Baba*" or "*Ma*," an affectionate way of saying father or mother, rather than calling them by their first names, as they feel they should be respected as elders. In some settings it might be acceptable for the nurses to call a patient by his/her first name, but in many cases it may be interpreted as disrespect by the patients and/or impose on the values of the nurses. In contrast, in the current study, nurses applied the acquired values critically, since their decisions were taken autonomously to care for patients suffering from AIDS, taking into account their diverse needs; hence their reasoning was integrated within a palliative care context. The caring approach the nurses adopted towards their patients was as if they were nursing their own parents, brothers or sisters.

In addition, the nature of work the nurses engage with on a daily basis is morally prescribed by their profession, as they are expected to comply with the wishes of the patients and their families, even though their values may not necessary be in agreement with their own (Zuzelo, 2007). Under these circumstances, indoctrination or some moral education (whether taught or modeled) is necessary for the personal development of the nurses so that the appropriate behavior as members of a professional body of nursing are displayed accordingly to address the unique needs of patients in need of palliative care (Tan, 2004). The findings of the current study revealed that the nurses' socialization background had inculcated values and norms that were applicable to the contextual needs of the terminal patients and, in this way, they did not only "*fit into their moral profession as carers*" (Zuzelo, 2007), but also contributed to the total well-being of their patients by meeting the expected cultural and emotional values of showing respect to their elders.

5.2.1.3 Caring as Transforming

It was evident from this study that the nurses perceived caring as a process of restoring hope and full recovery to the terminally ill AIDS patients. In a context where HIV/AIDS is still viewed largely as a terminal illness, a disease that has no cure, adherence to anti-retroviral treatment was promoted by the participants, thereby encouraging and supporting their patients to recognize that AIDS is a chronic illness that persists for an extended time during which they can still lead a relatively normal life, rather than perceiving AIDS as a terminal illness with poor prognosis.

Theories on transformational leadership, namely supportive leadership and personal recognition, recommend supportive strategies which advocate for individualized consideration by encouraging behaviors that facilitate subordinates' needs and

preferences such as showing concern for their welfare, thus creating friendly, supportive and therapeutic environments (Rafferty and Griffin, 2004). The participants in this study used supportive measures to re-establish a sense of hope and dignity to the patients who were in despair and refusing to take treatment, after having been diagnosed with HIV/AIDS. On admission to palliative care wards, the nurses remained patient with them, listened to their grief and advised them on the long-term benefits of antiretroviral drugs that reduce HIV related illnesses and death. In this way, the nurses were agents of change who facilitated a change in their patients' attitudes from a mind-set of gloom and fear of death due to AIDS, to a more positive frame of mind where they could have a future by adherence to the treatment. By paving a way to proper care, treatment and support of the terminally ill patients living with AIDS, the nurses gained victory over the negative stigma associated with AIDS through counseling, supportive care and promoting an enabling environment for disclosure, (Greeff, Uys, Holzemer, Makoe, Dlamini, Kohi, Chirwa, Naidoo, and Phetlhu 2008). Thus, the nurses in this study were instrumental in transforming the negative attitudes of fear, stigma and isolation that are attached to AIDS diagnosis and treatment interventions to positive attitudes of acceptance of a life-long condition through lifestyle changes, prevention of opportunistic infections and adherence to antiretroviral therapy beyond the palliative care setting.

It has been acknowledged that lack of supportive efforts in fighting the AIDS epidemic defeats the efforts to care for people suffering from AIDS. The South African Government, particularly in the mid-90s, obstructed this support due to bureaucratic restructuring of the new democratic government and denialism that argued that HIV did not cause AIDS, but that it was caused by socio-economic problems such as poverty and life-style choices. Thus, the doubt in the established

science of HIV/AIDS etiology and treatment led to disappointment and failure of initiatives and strategies addressing the epidemic (Bloor, 2012).

In the early period of the new millennium, however, the government launched the HIV testing and counseling campaign, thus changing the situation. Through appropriate state response, efforts were made to reduce the stigma around HIV testing through public speeches and open talk about HIV/AIDS, and increased access to antiretroviral drugs (Bloor, 2012). While the patients were being treated in palliative care wards, the nurses provided information on the benefits and the long-term complications of antiretroviral therapy, and also equipped them with the knowledge of how to deal with the problems of a chronic and life-threatening illness such as AIDS.

By transforming the attitudes of terminally ill patients through encouragement, supportive care and empathetic listening to their grief and suffering, the nurses made great strides in improving the quality of life of their patients and witnessed the reward of seeing patients' transition from terminal to chronic stages of the disease. Nurses were enriched by the gratitude of their recovering and discharged patients who had learnt to comply with the necessary adherence to antiretroviral drugs.

The South African National AIDS Council (2011) has expressed that positive progress has been made by the SA government in its target of reaching 80% coverage with antiretroviral drugs, and that 1,4 million people have been initiated on ARTS since their role-out in 2003. This has transformed the lives of patients ravaged by the debilitating effects of AIDS and revived their hope by prolonging their health through early HIV testing and treatment, from terminal to chronic stages of the disease. Nurses have shared in the sense of achievement and Bernard et al, (2001),

observed that the satisfaction of the nurses lies in the recovery of their patients from their illnesses. This was affirmed by the participants of the current study who saw their role in caring for patients who were terminally ill as a process of renewing hope by encouraging acceptance of their HIV status so that adherence to antiretroviral therapy was ensured for successful recovery. The nurses experienced a sense of personal reward, which they expressed as “*feelings of joy*” and “*feeling good*” as the patients’ psycho-social dimensions were transformed as they gained confidence and control over the management of their chronic disease.

5.2.1.4 Caring requires sacrifice

Expressing the meaning assigned to caring for terminally ill patients dying of AIDS in palliative health contexts, the participants stated that their commitment to caring involved practical actions and responses such as alleviating pain and suffering. Sometimes they had to forgo their own personal time and family lives in order to meet the unique needs of their dying patients. Acknowledging the nurses’ stance on the notion of self-sacrifice, Anthony and Barkell, (2008), highlight additional values that have been associated with nurses over the years that have influenced their practice, namely, self-denial, spiritual calling and devotion. The authors further maintain that due to religious ideals for a simple life and self-mortification, many nurses have been subjected to poor working environments and unfavorable remuneration packages and that they may find it difficult to assert themselves and insist on their rights to a safe environment and fair remuneration.

Participants in the current study acknowledged that the essence of caring meant total self-giving on their part for the well-being of the terminally ill patients. It was also voiced by the nurses that they saw their caring actions as the mind and the feet that

think and walk for those who are mentally and physically challenged due to the disabling effects of AIDS, and although they were draining at times, these were natural actions for them. The participants explained that patients' needs transcended their own. The older nurses spoke of times that they had been called back to work, often without pay, but acknowledged that this, however, no longer happens as they are paid for locums or sessional work when called back to work.

Apart from usual perceptions of care and self-sacrifice associated with the nursing profession, the unique background of this particular group of nurses might have enhanced their perceptions of self-sacrifice. Not only did the demographic data reveal that they were all Christians, but the institution under study has a Missionary influence, practicing Christian values of dedicated service to achieve the vision of Christ-centered care. Thus, the environment may nurture and support their values of sacrifice and dedication to continue rendering self-less quality care to the terminally ill with AIDS, without counting the cost of such actions on their own lives.

Anthony and Barkell, (2008), argue that there is no need for nurses to work under poor and unbearable conditions and they should not intensify self-sacrifice at the expense of self-care, but rather that a balance in life is fundamental for their total development. In addition, Zuzelo, (2007) warns that inadequate institutional resources and issues involving patient and professional conflicts cause psychological imbalance among nurses, leading to low job-satisfaction and retention within the organization. Echoing the research findings, the nurses in the current study said that restricted funding and dependence on locums, (sessional employees) oblige them to work long-working hours, at times to their detriment. They recognized that continued

work without rest or available counseling services impacts negatively on their performance and often results in exhaustion, which may lead to absenteeism.

According to the literature, recommended strategies that promote integrated self-sacrifice and self-care include maintenance of holistic approaches within the organization with a view to optimizing quality patient outcomes (Anthony and Barkell, 2008), and that the nurses' efforts should be recognized by rewards and acknowledgments of achieved specified goals (Rafferty and Griffin, 2004). Furthermore, Eriksson (2002) adds that the nature of caring is formed in a relationship between a patient and caregiver, thus if opportunities for self-development and care for the nurses are utilized, care delivery to patients will be strengthened, moved by an ethos of compassion and human love to alleviate suffering. The participants expressed the need for managerial support, such as training, counseling and recognition, to assist them in giving total self-sacrificing care to the terminally ill patients with AIDS.

5.2.1.5 Caring is holistic

Owing to the complexity of the disease its unpredictable course and comprehensive complications, the participants expressed that the care given to AIDS patients should be holistic, thus involving both physical and psychological aspects. It was explained by the participants that care-giving is demanding in that patients' needs are more diverse and complex in palliative care, with patients requiring pain relief; treatment of other symptoms, such as nausea, body weakness; counseling services to continue with ongoing HIV/AIDS services; psychological support so as to cope with psychological problems; and spiritual support to enable patients deal with fears of death and dying. As nurses also need to give support to the patients' families, and

sometimes their own relatives and colleagues who are infected and affected by AIDS, their resilience to cope with the burden is often depleted. The involvement of a multi-disciplinary team in palliative interventions is therefore imperative in order to balance the bio-psycho-social and spiritual dimensions of the terminal patients, integrating acute treatment with the control of chronic symptoms or problems.

Some researchers in caring science (Eriksson, 2002; Rytterstroem et al, 2009), support a comprehensive approach to patient care which strives to embrace an individual holistically. Elaborating on the importance of holistic nursing in creating therapeutic relationships among team members, McEvoy and Duffy, (2008) advocate for three main factors that add harmony, wholeness and healing to the clinicians, namely;

- Acceptance of the fact that health care is constantly changing, thus the socio-cultural changing environments of care need to be considered.
- Involvement of team work enables sharing of knowledge and understanding of each other's perspectives in the different disciplines, and curbs fragmentation.
- Empowerment of the patient is enhanced as they are given the opportunity to make choices that affect their care, thus utilizing their own inner resources.

By expressing a holistic approach to caring, the participants not only echoed the researcher's findings by referring to the first two factors, but also said that they delivered integrated and total care to the patients in the palliative wards, encompassing the entire person in body, soul and spirit. In addition, the inter-disciplinary team of doctors, nurses, social workers, dieticians and counselors

worked together in their specific roles to achieve quality patient outcomes. According to the field notes records, patients were not listed as part of the multi-disciplinary team, although their exclusion did not impinge on care given as their involvement was apparent in the individualized care plan records, noted by the researcher in patients' files. However, although the entire team is involved in comprehensive palliative care, it is important to prioritize patients as the center and key role players in the decisions affecting their care (WHO, 2011).

McEvoy and Duffy (2008:415) advocate for balanced holistic nursing and suggest that the nurses "*need to be aware of their own vulnerability through self-reflection on their own actions, and openness to other peoples' perceptions of themselves*" so that wholeness can be achieved for their well-being and that of their patients. The nurses in the current study admitted that caring for AIDS patients was very stressful as the patients they nursed were often very sick and dependent on their care or they were burdened with patient/relative problems, and there were no resources available to help them to de-stress and regain their coping and resilience skills. This resulted in feelings of hopelessness and frustration, which impacted negatively on patient care.

Anthony and Barkell, (2008) explain that the successful balance between caring for nurses and the demands of caring for others implies that nurse educators and nurse managers must work together in order to address the military approach that emphasis discipline and obedience at the expense of the nurses, and nurses must be encouraged to voice their opinions. Their stressors may thus be curtailed, creating a satisfactory work environment for the nurses and the patients, and quality outcomes that are patient-focused and non-intrusive (involvement in decision-making) are achieved respectively (McEvoy and Duffy, (2008). Facilitation of an

environment that supports and involves the nurses with the necessary resources to care for their patients may contribute in maintaining physical and psychological balance in their lives so that they can in turn continue rendering holistic nursing for the psycho-social well-being of patients affected by a complex illness such as AIDS.

5.2.2 CONCEPTUALIZING TERMINAL ILLNESS

Terminal illness was conceptualized into four attributes that were described as: 1) requiring long-term care; 2) requiring care to ensure patients have a peaceful and dignified death; 3) an opportunity for new learning; and 4) raising consciousness of HIV/AIDS. These are discussed below.

5.2.2.1 Terminal Illness requires long-term care

As has been illustrated in chapter four, one of the themes of terminal illness is that it requires long term care. Participants said that HIV/AIDS was no longer regarded as a terminal and killer disease, but rather as a chronic and manageable disease. They explained that the perception of HIV/AIDS has changed from being a short-term illness to being a long-term illness, like all other chronic diseases such as diabetes mellitus, hypertension and cerebro-vascular accident. The nurses believed that patients with chronic conditions can be helped to understand their conditions through educational activities and interventions of nurses or other caregivers and live normal lives. One of their functions in the palliative care wards, therefore, involved motivating patients with AIDS to persist in their prescribed treatment and helping them to maintain on-going quality care. This encouraged patients with terminal AIDS to monitor their progress and consult the expertise of the palliative care team to solve problems related to treatment interventions. Hence their terminal state improved to a chronic state and, as a result, some were discharged home.

With the emergence of effective antiretroviral therapy and palliative medicine there has been much improvement in HIV/AIDS management. The control of viral replication has led to a reduction in the premature death of patients suffering from AIDS (Selwyn 2005; South African National AIDS Council, 2011). Furthermore, it is an established fact that HIV positive patients who have access to treatment, with 90% adherence rate, have improved their quality and duration of life as compared to one or two decades ago (Masur and Bethesda 2009; South African National AIDS Council, 2011). Although all the participants in the current study still referred to their patients as “terminal patients”, the nurses explained that what they meant by this was that there is currently no cure for the disease. Along with the nursing care they provided, the nurses focused on educating their patients on the benefits of antiretroviral treatment, the dangers of not adhering to their treatment regimens and life-style changes. Many of the patients who complied with treatment recovered and their more positive attitudes displayed the hope that their lives had been prolonged, and that the effects of the disease had been transformed from being terminal to being chronic. The nurses’ perceptions of AIDS being a terminal illness was also transformed as they witnessed their critical, dying patients recovering to a chronic and stable state. They did say, however, that in some cases, their efforts to enhance the patients’ self-confidence in their ability to control their symptoms proved unsuccessful and the patients did not comply with their treatment plans and self-management interventions and consequently died fairly early in their course of antiretroviral treatment.

The World Health Organization, (WHO) (2004), highlighted a comprehensive educational package for the successful management of AIDS patients in palliative care contexts. The WHO’s strategy includes the following imperative key areas:

- Special precautions to be considered to prevent infection and management thereof.
- Awareness of the unpredictable course of the illness that can change at any time.
- Awareness of the complex family issues that may contribute to non-compliance to treatment, e.g. socio-economic factors and stigma.
- Sexuality education for the patients with AIDS.
- Adherence to antiretroviral drugs with specific guidelines on the management of specific complications.

While the participants' interventions focused on curative care in the hospital, with the key focus on antiretroviral adherence, according to the field notes, the bulk of the educational guidelines were neglected. In addition, based on the probes related to patients being discharged from the palliative care wards, no mention was made of educating patients on the prevention of infection or the importance of remaining healthy through safe sex and a healthy life-style. According to McEvoy and Duffy, (2008), fragmentation of health care services prevents the holistic care of patients with AIDS, leading to premature death of patients. Although the participants overlooked certain aspects recommended by the WHO, they did contribute to the well-being of their patients by listening to their problems, giving encouragement and emotional support, and gaining their co-operation and compliance to antiretroviral treatment. Through them, the patients gained confidence in the treatment and were able to be discharged from the palliative care wards for rehabilitation at home. As the nurses witnessed the transition of some patients whose death was inevitable, improving to the extent of being discharged, their perceptions of terminal illness changed from being related to patients who were dying and at the last stage of their

lives to patients who could resume their normal lives, sustained through antiretroviral therapy. Thus the conceptualization of terminal illness as requiring long-term care was based on the recovery of terminal patients. The attitudes and physical and psychological well-being of terminal patients were transformed and improved for the better through the nurses' interventions of caring, and giving hope and emotional support to patients suffering from AIDS.

Kell and Walley, (2009), arguing for the need for palliative care, acknowledge that chronic care is a relatively a new field of health care in most of sub-Saharan Africa and that most facilities have focused on acute and general care rather than special care. The setting of this study was an institution that is registered by the South African Department of Health as a level one district hospital offering general services to in-patient and outpatient services. As noted by the participants, although palliative care services were rendered for patients terminally ill with AIDS, the institution was not equipped to provide chronic palliative care services, particularly in terms of staff-training and equipment, thus impacting negatively on quality patient-outcomes. In spite of these shortcomings, however, the participants made the most of the available resources and gave of themselves in a way that reached out to the terminal patients, to be the eyes of those who could not see, the minds of those who were mentally impaired with AIDS and the feet of those who were bed-ridden, assisting them with their physical needs and providing the necessary nursing care. Those patients who had reached the final stages of the disease were nursed in a way that enabled them to maintain their dignity and die as peaceful as possible (as explained in depth in the next theme on terminal illness requiring care to ensure patients have dignified and peaceful death), while others gained a better quality of life by learning how to take control of their long-term disease.

It has been acknowledged that there is a general lack of palliative care despite the recommendations for its essential role in the management of antiretroviral drugs for improving the quality of life for patients with AIDS (Kell and Walley, 2009). Furthermore, it has been shown that nurses can change the perceptions of patients with AIDS and drastically improve their quality of life, despite organizational limitations, by promoting antiretroviral treatment which is the most effective palliation in HIV/AIDS management (Mngadi, 2006). A study conducted in oncology units by Lange et al, (2008) supports the findings of the current study that patients with AIDS who are diligent in managing their antiretroviral regimen can experience a better quality of life as it confirmed that a significant number of treatments within palliative care contexts can be successful, thus enabling patients to continue living their expected lifespan. In this study, the nurses' roles in providing dedicated and self-giving care, and the emotional support and hope they gave to patients who had been admitted into the palliative wards in despair, contributed to transforming their lives from being terminal to being chronic, and although requiring long-term care, they could be integrated back into their communities.

5.2.2.2 Terminal illness requires care to ensure patients have a peaceful and dignified death

In as much as terminal care was hailed in the previous theme as an opportunity to improve the quality of life for the terminally ill patients with AIDS, it was equally perceived by some participants as a way of assisting dying patients to die with dignity. Without undermining the value of the comprehensive approach of palliative health, the participants explained that some patients were admitted into palliative wards in a critical condition, where intensive care and therapy were no longer

effective for active resuscitation and there was no chance of survival. These patients were very ill and totally dependent on the health care providers for all their physical and spiritual needs and nothing could be done to restore their health. The participants explained that it was their role to maintain the dignity of the dying patients and try and make their last days as peaceful and comfortable as possible by administering the pain treatment ordered by the doctors and providing emotional support. Many patients admitted into palliative care delay in seeking help and arrive already in end-of-life stages, either dying or gasping, thus requiring less aggressive procedures (Kell and Walley, 2009).

A study by (Bernard et al 2001), assessing nurses' experiences caring for terminally ill patients with cancer, showed that the nurses experienced feelings of sadness and a sense of helplessness when their efforts to assist patients were no longer effective due to death or inability to control patients' suffering. Similarly the findings of a study by Smit, (2005), within the context of caring for terminally ill patients with AIDS, revealed that although the participants experienced symptoms such as fatigue due to prolonged contact with dying patients, they continued to provide extensive nursing care which involved physical care, pain relief and emotional support. In comparison, the participants in the current study appeared to have taken a more pragmatic stance accepting that death was inevitable in some cases. The nurses explained that when *"nothing could be done, except to assist in pain control,"* they did all they could to maintain the dignity of the dying patients and keep them as comfortable as possible thus assisting them to have a peaceful death.

Furthermore, a study conducted by Lange, et al, (2008) to assess the attitudes of nurses caring for dying patients revealed that nurses who had more years of nursing

practice, more hours of palliative care education and perceived death as a passageway to a happy life, had more positive attitudes towards the care of dying patients than those who feared death. All the nurses in the current study had been nursing for at least a year, and although only two had six months palliative care training, the nurses were all experienced in nursing and caring for dying palliative patients as the majority had an average of three to four years of experience in palliative care wards. The nurses were also religious, as their demographic information showed that they were all Christians. The participants also expressed that faith enabled them to cope positively with the care of dying patients and they viewed death as a preparation for the next life, as is elaborated in depth below on the theme on the mechanisms that enhanced the nurses' coping skills.

Although some authors have reported problems of poor pain assessments and under-treatment of pain as major challenges that contribute to difficulties in the care and management of dying patients (Selwyn, 2005; Kell and Walley 2009), in this study the nurses affirmed that through pain control, the terminally ill patients with AIDS were assisted to die comfortably and with dignity in the palliative care wards.

5.2.2.3 Terminal Illness is an opportunity for new learning

AIDS provided the participants with opportunities for new learning as new skills and knowledge were acquired so as to care and support all those affected and infected by the disease. Apart from basic information within the nursing curriculum regarding HIV/AIDS, caring for terminally ill patients equipped the nurses with job-specific training to address specific patient-driven needs. Through the availability of courses organized by their institution, such as advanced HIV/AIDS management, and counseling and bereavement courses, the nurses were able to assess the complex

opportunistic infections presented by AIDS, provide appropriate diagnosis and implement the specific care required by their patients and relatives in order to meet the challenge of improving quality palliative care delivery.

According to USAID (2009), training within palliative care settings, particularly in the developing world, needs to focus not only on doctors and nursing professionals, but also on lay people. USAID support was evident in the advocacy workshops organized by the African Palliative Care Association (APCA), whereby ten southern African countries were represented with 86% of participants expressing that the workshops strengthened and added value to palliative health services, (USAID, 2009). Specifically, training activities that include management of opportunistic infections, adherence counseling and caregiver support are an added benefit to the health care workers and keep them motivated to respond to the escalating burden of diseases in ever changing public health needs (Zachariah et al 2008). Therefore, the availability of training programmes in the current study enhanced the participants' skills to meet the clinical needs of the terminal patients with AIDS and increased their competencies in palliative care delivery.

Furthermore, the WHO (2004) has introduced an integrated approach to HIV/AIDS care and management strategy through the development of the Integrated Management of Adolescent and Adult Illness (IMAI) guidelines. However, although the guidelines provide a holistic approach which includes acute care, community care and capacity building through decentralization of antiretroviral therapy, the shortage of health care workers, worsened by the high burden of infectious diseases (Zachariah, et al, 2008), pose difficulties in addressing and integrating palliative care demands (USAID, 2009). Despite limitations in staffing and other resources

experienced by the participants in this study, their efforts to integrate patient-driven needs and the AIDS-focused opportunities into quality individualized palliative care will continue to grow through supportive training and guidance to improve patient care outcomes in palliative health contexts (Bausewein et al, 2011), and equip the nurses with up-to-date knowledge in their practice as required.

5.2.2.4 Terminal Illness raises consciousness on HIV/AIDS

The participants expressed that in spite of the treatment progress made in HIV/AIDS management, the ultimate outcome for most patients infected with AIDS is death. The nurses explained that while some patients may recover from their AIDS-related symptoms with appropriate treatment, others experience increasing health problems and progressively worsening illness, caused by life-threatening opportunistic infections, leading ultimately to severe immuno-suppression and death. Exposure to the reality of death of patients under their care raised the participants' awareness about the meaning of life and their own mortality. The nurses engaged actively with the death of their patients, as evidenced by the reflective extracts with introspective questions on their own mortality (Refer Chapter 4, sub-theme 2.4), resulting in empathetic and conscientious care to achieve quality palliative care outcomes for the terminally ill patients with AIDS.

A study conducted by van Rooyen, Williams and Ricks (2009) on lived experiences of caregivers working with patients dying from AIDS, revealed myriads of emotions experienced by the participants at various times in the disease trajectory. Accordingly, some caregivers found it difficult to accept the death of dying patients and perceived bonding with them as a threat to their psycho-social well-being, resulting in feeling drained and experiencing burnout. Others, however, perceived the

death of dying patients more positively as an experience that facilitated mental and spiritual growth, describing it as Gods' will that was beyond their control. The participants in the current study concurred with latter view, taking part in patients' deaths and listening empathetically to them in order to experience their world view. With an emic perspective into the patients' inner world, the participants became more caring and loving towards them with the hope that the biblical principle, "*do unto others what you would like done to you*" would be evident on their own death-bed and that they would be treated likewise. Hence the nurses were conscious of their own mortality as a reality to the human existence through their exposure and care for the terminal patients with AIDS in palliative care context.

Many nurses expressed the care of terminally ill patients with AIDS as a rewarding and fulfilling experience which helped them to provide quality care in a non-judgmental manner (Smit, 2005). The nurses in current study demonstrated caring and non-judgmental attitudes towards the terminal patients with AIDS, as they were aware of their own mortality as part of the human race.

5.3 EXPERIENCES OF CARING IN THE CONTEXT OF PALLIATIVE CARE

When exploring the nurses' experiences of caring in the context of palliative care, their experiences were conceptualized into the following three themes: 1) the social networking system; 2) hindrances in the context of HIV/AIDS; and 3) mechanisms of adjusting while caring for terminally ill patients with AIDS. Each of the themes has sub-themes and these are discussed below.

5.3.1 SOCIAL NETWORKING SYSTEM

Emerging from the data, it is evident that the participants recognized that effective palliative care requires a broad inter-disciplinary approach in order to maintain

collaborative communication between the patient and the palliative care team to improve the quality of life for the terminal patients with AIDS. The theme is further divided into a sub-theme, expressed as mutual support and is discussed below.

5.3.1.1 Mutual Support

The data revealed that the participants believed working collaboratively alongside other interdisciplinary teams and maintaining a harmonious relationship between members of the palliative care team were necessary for successful delivery of palliative care outcomes. In this way all team players could participate in the sharing of knowledge, skills and expertise among the different disciplines, and in identifying and implementing appropriate interventions to address individualized patient needs. According to the participants, this built therapeutic relationships among palliative care team members and enhanced patient outcomes.

In the light of the exacting and demanding nature of care rendered to patients living and dying of AIDS, nursing care involves providing extensive physical and emotional support to the terminally ill patients (Smit 2005). Furthermore, Munro and Edward, (2008:123), arguing for the needs of the patients, add that “*the nurses need to have an understanding of intimate interpersonal relationships in nursing,*” so that they can maintain therapeutic relationships by taking into account the individual needs of not only the patients, but also their loved ones. Rafferty and Griffin, (2004), on the other hand, advocate for the needs of the nurses, urging leaders to use supportive leadership skills that focus on addressing individual staff needs in order to maintain a friendly supportive work environment.

The participants in the current study identified creative ways of adjusting within their challenging palliative care context. By implementing a team approach in the delivery

of palliative services the nurses adopted different interactive methods such as humor, to lighten difficult situations encountered in the day, and team work, by giving assistance whenever a team member was unavailable for work, thus strengthening and building collegial relationships. The palliative team also collaborated with other professional disciplines that were involved with the care of their patients, thus sharing skills, ideas and time and acknowledging respect for the diverse needs of their professional social networks to optimize palliative services for the terminal patients with AIDS.

Within the palliative care teams and the inter-disciplinary teams, the participants created mutual supportive relationships and used humor to contribute positively to the challenges of caring for terminally ill patients with AIDS (Munro and Edward, 2008) in order to achieve quality patient outcomes in a friendly palliative care context.

5.3.2 HINDRANCES TO CARING IN THE CONTEXT OF PALLIATIVE CARE

Evident from the presentation of results, caring for terminally ill patients with AIDS present manifold barriers for the nurses related to physical challenges that involve issues related to the provision of patient care and psychological issues caused by having to adjust to human suffering and death. Six sub-themes emerged from the data analysis and included: 1) the overwhelming effect of AIDS; 2) fear of infection; 3) imbalances in the health care system; 4) HIV/AIDS described “as just another common condition,” 5) antecedents that alter levels of caring; and 6) caring conflicting with the need for money. These issues are discussed below.

5.3.2.1 The overwhelming effect of AIDS

Although the participants were resilient to the inherent challenges of caring for patients with AIDS, as expressed in sub-theme on accepting AIDS as a reality,

through a positive mind-set, episodes of feeling overwhelmed by the psycho-social dimensions of the disease were nevertheless unavoidable at times, resulting in a reduced ability to cope in palliative care contexts. They expressed that feelings of being overwhelmed were often the result of the prolonged nursing activities required by patients in the palliative wards; spiritual frustration of having to deal with the emotional burdens of the AIDS patients and their relatives; and feelings of social isolation and helplessness as a result of having little support in addressing their own emotional needs. The nurses explained that in such cases, their feelings of anger and helplessness made it difficult for them to cope effectively with the demands of their patients.

Sub-Saharan Africa is overburdened with a multitude of chronic diseases such as cancer and other non-communicable diseases, adding to the burden of the progressive and life-limiting HIV epidemic, (Selman et al, 2011). As a result, there are many demands made on nurses taking care of patients who have physical and cognitive disabilities as they have the responsibility of providing interventions to address the needs caused by patients' illnesses and disabilities (Herbert, Robert, Arnold and Schulz, 2007). This is congruent with the nurses' experiences in the current study. Due to the nature of care required by the patients who are bed-ridden, the nurses executed demanding nursing activities such as blanket baths, cleaning up incontinent and vomiting patients, feeding them and listening to their emotional problems and, in addition, still handling the demands of the relatives. It was inevitable, therefore, that while caring for terminally ill patients with AIDS, the nurses would experience periods of intense emotion that overpowered and drained them at various levels, affecting their spiritual, emotional and physical wellbeing.

It is widely known that South Africa and Uganda are the two countries in sub-Saharan Africa most advanced in the provision of palliative care (Selman et al, 2011). However, it became evident in this current study that financial restrictions and staff shortages hindered the delivery of quality palliative care to the terminal patients. The nurses wished they had more time available to engage in conversations with their patients to raise their awareness of HIV/AIDS and to promote its prevention.

Generally, terminal patients with AIDS have psycho-social concerns that have “*spin off effects, not only on the patients, but also to their families and carers,*” (Jameson, 2007:849). This relates to the fact that patient suffering and caregiver well-being are closely related and intertwined (Hebert et al, 2007). However, despite the physical and psychological effects experienced by the nurses in caring for terminal patients, they remained positive on the whole, desiring to do more and going the extra mile for their patients in order to achieve quality palliative care delivery.

5.3.2.2 Fear of infection

The participants noted that the risk of infection was one of the challenging aspects of working in palliative care wards and that it did have a negative effect on them. The nurses explained that working in an environment of debilitating infectious diseases such as AIDS and Tuberculosis (TB) was stressful, due to their fear of contracting the infections and that this consequently affected the manner in which they administered care.

This is supported by the results of a study conducted by de Villiers and Ndou, (2008), who found that nurses experienced difficulties in caring for HIV/AIDS patients due to their fear of contracting the disease. This current study revealed that the patients who were in denial of their HIV positive status exacerbated the problem by failing to

take protective measures when coughing or resending the nurses' wearing of gloves. The nurses persevered in caring for patients, however, and continued using protective measures, such as the gloves, while rendering care, in order to reduce the risk of contracting the virus.

Although the participants experienced emotional fears and challenges while caring for terminally ill patients dying of AIDS, they discovered their own coping strategies and were able to transcend their situations by adopting positive and caring attitudes towards their patients (de Villers and Ndou, 2008, Munro and Edward 2008; van Rooyen et al, 2009). Thus, through these strategies and the use of protective measures, the nurses persisted in working in palliative care wards and continued to render safe and quality palliative care services to terminal patients infected by AIDS.

5.3.2.3 Imbalances in the health care system

Recognizing their role as health providers in the context of palliative care, the nurses acknowledged that the enormity of the HIV/AIDS epidemic had a negative impact on the delivery of nursing care. Imbued with the goals of enhancing the quality of life for terminal patients by meeting their health needs, the participants became frustrated when their efforts were hindered and patients who could have been saved, died. Institutional limitations such as shortage of staff and inadequate equipment impeded the nurses' abilities in achieving and delivering quality nursing care for their palliative care patients.

Globally, health care institutions, particularly hospitals, are essential "*vehicles for the delivery of health care*" and managers are entrusted with the tasks of implementing the visions and objectives that policy makers have for the health and well-being of the nation (Pillay, 2010:2). Public health organizations, however, face many

challenges. The Nursing Strategy for South Africa, (2008), has explicitly highlighted that the shortage and loss of skilled professional nurses has resulted in a decline in the standards of nursing care, and the need to improve the quality of health care has been worsened by the burden of diseases, particularly in the context of HIV/AIDS. Although the institution under study is not a public hospital, but a private state-aided hospital, it is equally affected by the global issues affecting the health care sector, namely, the shortage of skilled nurses and equipment, thus limiting the nurses' abilities to care for their patients and sometimes resulting in deaths that could have been avoided.

Zuzelo, (2007) taking account of the nurses' position, further clarifies that nursing, as a morally inclined profession, seeks to fulfill ethically focused goals related to protecting patients, providing care and preventing complications, thus experiences of moral distress are likely to occur if societal, organizational, medical and individual constraints prevent them from meeting the quality care of their patients. Frustrated by their inability to deliver adequate nursing care to their patients, the nurses engage in introspective questions, such as, evaluating their nursing care plans and seeking answers from the policy makers of the nursing care standards of their profession in order to continue giving care to palliative patients.

This was evident in the current study where, amidst global, professional, institutional and personal limitations, the nurses sought to sustain the provision of palliative care for their patients and relatives by doing their utmost to cope with the challenges by identifying strategies to overcome them and engaging in moral questions affecting their profession.

5.3.2.4 HIV described as “just another condition”

In the context of palliative care that dealt with other chronic conditions, namely, Diabetes Mellitus and Hypertension or Cerebro-Vascular Accident (as explained further in the extracts on terminal illness requiring long-term care) other than AIDS related conditions, the nurses realized that most terminally ill patients admitted in their wards had HIV/AIDS as the underlying cause. The nurses were exposed frequently to the diseases such as TB and Pneumonia that required almost the same antiretroviral treatment, and realized that these were essentially AIDS opportunistic infections. While some participants perceived working with patients with AIDS as an opportunity for new learning as expressed in the theme above, others described their work as monotonous, self-limiting and non-stimulating and felt that their academic progress was restricted due to the lack of diversity in the nursing care activities rendered to their patients with AIDS.

According to Masur and Bethesda (2009), it is generally known that most patients admitted in patients' care units have HIV or need AIDS related treatments, due to HIV/AIDS being the underlying cause, thus clinicians need to consider HIV infection as one of the major factors in their short-term and long-term assessments of patients. This empirical evidence supports the participants' perceptions in the current study that Tuberculosis and Pneumonia were almost synonymous to HIV/AIDS and assists in the understanding of their personal challenges in rendering quality nursing care to patients with AIDS. In this study, particularly in this theme, the nurses were AIDS fatigued, as they perceived patients suffering from the disease as an impediment to their academic development and stimulation. In other words AIDS was no longer an interesting agenda for their learning.

5.3.2.5 Antecedents that alter levels of caring

Recognizing the primary goal in palliative health is maintaining the quality of life for terminally ill patients, the participants expressed that it was important that the nurses executed optimum nursing care standards to maintain acceptable levels of care. They pointed out, however, that the historical background of the nurses in palliative care should be taken into account as some of them may have had personal experiences of abuse or HIV infection which could have a negative influence on their provision of care, thus impeding effective and efficient service delivery in palliative care contexts.

A study by Kang'ethe (2009), evaluating the challenges impacting on the quality of care to persons living with AIDS, showed that caregivers complained mainly about lack of external resources, such as limited financial resources and the unavailability of materials, and blamed these factors for the resultant high deaths among palliative care patients and low quality of care. While these factors were acknowledged by the participants in the current study, they observed that internal factors involving the personal lives of the nurses may also encroach on their performance, resulting in poor quality care being delivered to terminal patients.

Pisaniello, Winifield and Desalbbro, (2012), argue that social support from supervisors is an antecedent to emotional expression in order to promote nurse-patient relationships (emotional work) and supersedes emotional labor which focuses more on emotional suppression. These authors further explain that if the nurses are given a space to express their emotions, it will enhance working relationships and contribute to the well-being of patients and staff members, whereas suppressed emotions simply add to job-dissatisfaction in the work place. Similarly, it emerged

from the data analysis that the nurses' personal experiences need to be explored before labeling them as having negative uncaring attitudes as the suffering and death of significant family members and historical events of violence can have an effect on their attitudes towards palliative patients. With the help and support of management, these nurses can be molded into caring professionals.

According to Rafferty and Griffin, (2004), a supportive leader will facilitate behaviors that stimulate interest in the work place and encourage awareness of problems and strengthen the ability to resolve them creatively. It is therefore necessary to focus on the needs of the individual nurses taking into account their personal experiences that might alter their levels of caring. Taking into consideration the antecedents of their past experiences may enhance positive nurse-patient relationships in the care of terminally ill patients with AIDS, while increasing interpersonal care within palliative contexts (Munro and Edward, 2008). In the current study, the nurses highlighted internalized emotional issues of the nurses and suggested that not only the external organizational issues need to be addressed to promote caring attitudes among staff members, but that the individualized needs of the nurses also need to be taken into account. Thus the emotional antecedents that alter the personal levels of caring are an agenda that need to be addressed in order for nurses to work in an emotional environment such as palliative care and will not only improve nurse-patient relationships, but ultimately enhance the nursing profession as a whole (Pisanello et al, 2012).

5.3.2.6 Caring conflicting with the need for money

Participants expressed that meaningful recognition of their caring roles for terminally ill patients establishes and maintains a healthy nurse-patient relationship within the

palliative care settings. However, while they acknowledged that good salaries contributed to positive outcomes such as job-satisfaction, they also noted that nursing was more of a calling than a job and that if too much focus was placed on money issues, it could lead to poor quality of patient care in palliative care wards.

A study conducted by Mulaudzi, Pengpid and Peltzer (2011), assessing the knowledge, attitudes and coping strategies of nurses caring for patients with AIDS found that the nurses felt they should receive meaningful recognition of their work as carers for terminal patients. According to their findings, over half of the nurses (55.1%) stated that caring for patients with AIDS is more stressful than nursing other patients and 59.4% felt that nurses need an extra allowance for caring for patients with AIDS. With regard to the nurses in the current study, however, none of them expressed the need for an extra allowance. They did express, however, that wages should be in keeping with work performed and it is important that nurses' wages should be appropriate to the services they render in caring for terminally ill patients.

Although the healthcare system is classified as administering essential services, the reality is that even nurses and doctors become involved in salary negotiations and national strikes, thus neglecting the human and ethical rights of their patients in the process by compromising their basic health needs (de Villiers, 2010). The participants of this current study raised the concern that many nurses are more focused on their salary than their work, which leads to job dissatisfaction and compromises the delivery of quality patient care.

In conclusion, nurses need fair recognition and support while caring for terminally ill patients with AIDS (Mulaudzi et al, 2011), in order to reduce dissatisfaction in the workplace and provide them with the emotional support they need to carry out their

duties efficiently (de Villiers 2010). Although nursing is perceived as a calling, nurses need money to live on and should receive wages that are in accordance with the important function they perform in taking care of terminally ill patients.

5.3.3 MECHANISMS OF ADJUSTING WHILE CARING FOR TERMINALLY ILL PATIENTS WITH AIDS

Participants expressed that there are job-related stresses associated with caring for the terminally ill patients which they find challenging, one of the most important being that they have to come to terms with human suffering and death. Because of the high number of people with AIDS-related illnesses, the nurses in the palliative wards have a heavy workload as prolonged and time-consuming nursing activities are required by their patients. Furthermore, nurses lack the emotional support they need while caring for terminally ill patients. To overcome these challenges and remain effective and productive in their work, the participants developed internal and external coping strategies that assisted them to adjust in the care of terminally ill patients. Some of their strategies included praying to God to sustain their strength, a genuine love of their patients and their job, implementing the golden rule by trying to do good at all times and sharing their experiences of caring for terminal patients. By integrating these strategies into their work, the nurses reduced their stress and made their duties more manageable, to the mutual benefit of themselves and their patients.

Tuncay, (2007) conducted a study to explore the role of spirituality in coping with HIV/AIDS as a chronic illness. This researcher found that spirituality plays a significant role in enhancing the coping abilities of health care workers with the psychological and emotional effects of HIV/AIDS. In addition, the results also

indicated that spirituality encompasses tolerant and pardoning attitudes and religious practices, such as prayer and worship which contribute to holistic wellness. The nurses in the current study expressed that their religious practices enabled them to perceive their patients as the image of God which helped them to cope with work pressures such as ungrateful managers and dying patients. Therefore coping strategies that include self-efficacy, well-defined faith, and support networks, such as the presence of at least one person who portrays an attitude of listening and compassion, enhance resilience and provide support and adaptation for people living with HIV/AIDS (PLWHA) and their carers (Munro and Edward, 2008).

HIV/AIDS suffering and death is particularly taxing and draining for the care-givers, (Smit 2005) and there are emotional challenges such as sadness and pity when the patients are dying of AIDS, which may be unavoidable for those who are caring for them (van Rooyen et al, 2009). In a study conducted by Mulaudzi et al, (2011), assessing the nurses' knowledge, attitudes and coping abilities in caring for patients with AIDS in the rural hospitals of South Africa, these authors argued that the AIDS epidemic had increased the nurses' workload. Their results revealed that the majority of the nurses (68.3%) found it more demanding to care for patients with AIDS than other patients and more than half (52.7%) felt that their work situation had worsened since the AIDS epidemic. The study setting in the current study is a state- aided level one district hospital. Because of its location, it is the only district hospital serving a large population of 750 000 people, of which over 60% are infected by AIDS. The hospital has a 100% bed occupancy rate and at times more than this (Hospital Stats, 2010). The volume of patients in this semi-rural hospital is overwhelming and nurses are faced with many challenges in providing quality care to terminally ill patients. These nurses, however, have implemented meaningful coping strategies that have

helped them to retain meaning in their lives, prevent burnout from the emotional stresses of their jobs and care for patients suffering from AIDS.

The theme had a sub-theme, discussed below, as accepting death as a reality of life in the context of caring for patients with AIDS.

5.3.3.1 Accepting death as a reality of life

The participants expressed that despite the increasing acknowledgment of the importance of palliative care in the management of terminal patients with AIDS, the nurses were not always successful in preventing AIDS related deaths in palliative care units. Some patients with advanced AIDS defining complications arrived into the wards in a critical condition and their deaths were inevitable. Having no control over the circumstances, the participants had to face the fact that AIDS related deaths are a reality of life in the context of palliative care. Knowing that AIDS is a chronic disease with no cure helped the participants to come to terms with the deaths and continue in their work of providing care to terminally ill patients.

Mngadi, (2006), argues that although antiretroviral treatment (ART) has shown a successful transition of AIDS from a terminal to a chronic disease state, cost issues hinder the progress of successful outcomes in palliative care as ART is neither free, nor available to 90% of people living with AIDS in sub-Saharan Africa. Therefore, millions of people are living with the disease and are subject to increasing impairment of the immune system which, worsened by opportunistic infections, often results in premature death. Consequently, the nurses in the current study were confronted with a situation that was beyond their control, that is, reviving the lives of immuno-suppressed patients admitted into palliative care wards. Death occurred on a daily basis and was therefore experienced as a reality of life. As the nurses could

neither change the reality of their situation, nor abscond from it, resorting to an attitude of acceptance and care for patients in their terminal stages was a form of rationalization as a means of survival and coping with the magnitude of suffering and death of patients with AIDS (van Rooyen et al, 2009).

Conversely, some participants expressed some concerns that the acceptance of death as a reality of life had a negative effect on some of the nurses, especially the younger ones. They explained that routine exposure to death and dying accustoms nurses to dealing with death, and leads to situations where they display lack of care and respect for the dead by giggling or chatting while handling the corpse or transporting it to the mortuary.

In the study conducted by Mulaudzi et al, (2011) to assess the knowledge, attitudes and coping of nurses related to the care of patients with AIDS, the findings showed that 75,8% of the nurses had positive attitudes towards caring for patients with AIDS, while a minority of 5.9% had very negative attitudes. Furthermore, findings also revealed that nurses with more than 10 years of experience were able to cope better in caring for terminal patients with AIDS than the nurses with less than 10 years of experience. The current study showed, however, that most of the nurses, regardless of their experience, were concerned about the uncaring attitudes of some of the nurses. In fact, the demographic data of the nurses showed that although the two senior nurses had spent at least 20 years caring for terminal patients with AIDS, the majority of the nurses had less than 10 years of experience. There was a general concern from each of the categories (below and over 10 years) of experience, that due to their exposure to suffering and dying patients, some nurses developed a

hardened and uncaring approach to patients which impacted negatively on patient-focused care in the palliative wards.

According to Munro and Edward, (2008:126) "*The experience of resilience does not result from avoidance of risk rather it stems from the exposure to risk through successful problem-solving.*" The participants in the current study have proved this. Although they are exposed to challenges inherent in caring for terminally ill patients with AIDS, namely the reality of death, institutional constraints, staff with uncaring attitudes and patient overload, they have tapped into their internal and external resources as coping strategies and became resilient in continuing care for AIDS patients in palliative care contexts.

5.3.4 CONTRIBUTIONS OF THE CURRENT STUDY TO SCIENTIFIC KNOWLEDGE

5.3.4.1 What is already known about the topic

A. There are various existing conceptions of caring and terminal illness which have been confirmed in this study. These are illustrated below:

Caring as value system:

- Caring is described by Eriksson, (2002) as an intrinsic value, driven by a caritas motive. However, Rytterstroem et al, (2009) added that it is possible to provide care to the patient, without necessarily including love. In this study, the participants were moved by love of patients and their job, which were motivating and fulfilling values for them.

Caring conflicting with the need for money:

- Mulaudzi et al, (2011) highlighted that nurses caring for terminally ill patients with AIDS need recognition in the form of an additional allowance. While the nurses in the current study expressed that they needed salaries for personal survival, this motive was not expressed as overriding their primary choice of the nursing profession which includes giving care to terminally ill patients.

Caring is Holistic

- Various researchers in the caring science support a comprehensive approach to patient care and recommend that care should embrace an individual holistically, mind, soul and body (Eriksson, 2002; Rytterstroem et al, 2009). The nurses in the current study expressed that the care rendered to terminally ill patients with AIDS involved the psycho-social dimensions of the patients as they had complex emotional issues to be addressed by the interdisciplinary team of the palliative care.

Terminal Illness is long term care:

- With the emergence of effective antiretroviral therapy and palliative medicine much improvement has been noticed in HIV/AIDS management. The control of viral replication has led to a reduction in pre-mature AIDS related deaths (Selwyn 2005; South African National AIDS Council, 2011). Hence the nature of the AIDS has changed from being terminal to being a chronic, lifelong disease (Mngadi, 2006). By promoting antiretroviral treatment to patients admitted to palliative care, their health improved and they were discharged.

B. Experiences of caring in the context of terminally ill patients with AIDS:
(hindrances to quality care).

Fear of Infection:

- A study by Smit (2005), de Villiers and Ndou, (2008), Munro and Edward (2008); van Rooyen et al, (2009) showed that nurses experienced difficulties in caring for HIV/AIDS patients due to their fear of contracting the disease. Similarly, this current study revealed that the nurses experienced difficulties working in palliative wards which was worsened by patients that were in denial of their HIV positive status who refused to accept nurses wearing gloves or failed to take protective measures when coughing.

Imbalances in the health care:

- Globally, health care institutions, particularly hospitals, face many challenges related to shortage of staff, ineffective managers and lack of equipment (The Nursing Strategy for South Africa, 2008; Pillay, 2010). The nurses in the current study experienced similar challenges in their nursing care activities which resulted in patient deaths.

The overwhelming effects of AIDS

- The concept of the overwhelming effects of caring for patients with AIDS is not new in literature and causes helplessness and distress at not being able to alleviate the suffering of dying patients (Smit, 2005; van Rooyen et al, 2009). Although the nurses in the study experienced overwhelming physical and psychological challenges in caring for terminal patients with AIDS, they expressed the desire to do more and go the extra mile for their patients in order to deliver quality palliative care. The nurses highlighted organizational

issues such as staff shortages and limited resources as hindrances to rendering nursing care.

Mechanism of coping in the context of caring for terminally ill patients:

- HIV/AIDS suffering and death is particularly taxing and draining for the caregivers (Smit 2005). In a study by van Rooyen et al, (2009) the nurses adopted faith and prayer as coping mechanisms, and humor was identified as assisting coping in the care of terminal patients (Munro and Edward, 2008; Mulaudzi et al, 2011). Despite the challenges associated with palliative care in the care for terminally ill patients, the nurses in the current study identified meaningful coping strategies such as prayer and humor as having helped them to maintain meaning in their lives, prevent burnout from emotional stress and care for patients suffering from AIDS.

Accepting death related to HIV/AIDS as reality:

- A study by van Rooyen et al, 2009 found that the nurses who resorted to an attitude of acceptance and care for patients in their terminal stages was a form of rationalization, as they could not run-away from patient care. Likewise, in this study, the nurses identified that in order to survive working in the palliative wards and cope with the high volume of suffering and death that they are continually exposed to, they had to change their mind-sets and accept that death is a reality of life.

5.3.4.2 What this study adds to the body of knowledge:

The following has been brought to the fore based on concepts of terminal illness and the lived experiences of nurses in the care for terminal patients.

1. Terminal illness requires long-term care:

- It was noted that the patients who complied with the nurse's educational interventions focusing on the benefits of the antiretroviral treatment and the dangers of not adhering to their treatment regimens experienced life-style changes, recovery and discharge from hospital, while those who refused to comply died as a result. Although AIDS is terminal, in the sense that there is no cure, the life-span of the patients can be prolonged through ARTS and emotional support.

2. Terminal Illness requires care so that patients die peacefully with dignity:

- In the literature review, ways of assisting with dying are associated with euthanasia. In this study however, the nurses assisted their terminally ill patients to die by simply helping them to retain their dignity, keeping them as comfortable and peaceful as possible and through pain control.

3. Terminal Illness as an opportunity for new learning:

- Apart from the curriculum provisions with HIV/AIDS basic information, the exposure to the care of terminally ill patients equipped the nurses with job-specific training, to address specific patient-driven needs, e.g. through bereavement and counseling courses.

4. Terminal illness raises consciousness on HIV/AIDS:

- The nurses became conscious of the reality of their own mortality through their exposure to and care for the terminal patients with AIDS in palliative care context.

5. Experiences of nurses caring in palliative settings:

5.1 Social networking:

- The nurses recognized that effective palliative care required a broad interdisciplinary approach in order to maintain collaborative communication between the patients and the palliative care team to improve the quality outcomes for the terminal patients with AIDS.

5.2 HIV described “just as another condition”

- Although Masur and Bethesda (2009) confirmed that most patients admitted into patients’ care units have HIV or need AIDS related treatments due to HIV/AIDS being the underlying cause, thus warning clinicians to be vigilant in their assessments of patients, the nurses in the current study perceived patients with TB and Pneumonia as synonymous to HIV/AIDS, as all patients received antiretroviral treatment. The nurses highlighted the description of HIV as “*just as another condition*” as a hindrance that alters their level of caring as it was perceived as monotonous care and limiting their academic progress due to lack of diversity.

5.3 Antecedents that lower levels of care:

- In the current study, the participants highlighted that the fact that nurses may have internalized emotional issues, such as experiences of violence, abuse and personal infection with HIV, which would hinder their ability to provide quality care, and suggested that particular focus needs to be drawn on meeting not only the external organizational issues, but also the individualized

needs of the nurses with a view to promoting caring attitudes for terminally ill patients with AIDS.

5.4 Comparing oncology and palliative care units

- Findings from various studies have revealed that caring for cancer patients is comparable to caring for AIDS patients in many respects. According to Bernard et al, (2001) and Lange et al, (2008), who conducted research in oncology units, registered nurses who have had longer exposure to the care of dying patients have more positive attitudes toward caring for dying patients than the younger nurses with limited exposure. Similarly, Mulaudzi, et al, (2011), in the context of caring for terminally ill patients, stated that nurses with over ten years of experience had more positive attitudes than those with less than ten years. In the current study, all the nurses, regardless of their age, had more than one year of experience in a palliative care setting of patients with AIDS and expressed positive attitudes towards death, seeing it as a preparation for a happy after life. The nurses' experiences with respect to death were also similar. Nurses caring for both cancer patients and AIDS patients experienced feelings of sadness or helplessness due to their inability to assist the dying patients (Bernard et al, 2001; Smit, 2005), respectively. The current study showed that although nurses adopted a strategy to accept death as a reality of life, there were times when they became overwhelmed with the effects of caring for the terminally ill, particularly if they died prematurely or died very young.

5.4 STRENGTHS AND LIMITATIONS OF THE STUDY

5.4.1 The strengths

The strengths of the study were based on the research methodology and research approach that were used, and are summarized as follows:

A qualitative study is a flexible study; as it investigates a phenomenon in a holistic approach (multiple realities versus single source of truth). Thus the strength of this study pertains to its phenomenological nature, in that the participants' own words were used by the researcher to describe their lived experiences of caring for terminally ill patients with AIDS. This is the first study that has been conducted on the experiences of the nurses caring for terminal patients in the palliative care wards in the facility of study and generated new information which may assist nurse managers, nurse educators and hospital administrators to develop and incorporate educational programmes in their policies and curriculum, respectively, that teach effective coping strategies that are aimed at preventing death anxiety among nurses, especially those with little or no experience in the care of terminally ill patients and their families.

5.4.2 The limitations

The limitations identified in the study included the following:

The sampling technique proposed for use was purposive sampling, which may not be representative of the general population and this means that the researcher cannot generalize the study to other settings outside of the study since is not necessarily representative of the population. However, qualitative studies do not seek to generalize study findings, but rather to transfer results for use in a similar context. Most of the articles accessed were Euro-centric as there was little literature available

pertaining to the South African context. Additionally the context of the study settings for most articles obtained was in hospices, home care or oncology units indicating gaps in knowledge, which the researcher hoped to close by generating new information.

The Husserlian Phenomenology is criticized for its influence with the positivist paradigm which uses a rigorous scientific approach in pursuit of truth, (Lavery, 2003). Applying this phenomenology in this study, the researchers' opinion or experiences in caring for terminally ill patients had to be disclosed, through conscious reflection or bracketing to avoid influencing the nurses' experiences. However, in the context of this study, it was important to understand the nurses' lived experience in caring for terminally ill patients in their own perspectives in order to optimize the quality care of these patients.

5.5 RECOMMENDATIONS

A number of key recommendations emerged from the study and will be discussed as follows: clinical recommendations; education and professional recommendations; managerial and policy recommendations; and research recommendations.

5.5.1 Clinical recommendations

Some patients took offence when the nurses used protective devices when caring for them, and they felt the need to be involved in their care needs. It is important that the clinicians, including doctors and nurses, keep the patients informed about their illnesses, prognosis and the prevention strategies to enhance not only patients' understanding, but also to ensure their cooperation in the disease trajectory. Findings of various studies have highlighted that it is more important for patients in palliative care settings to have a sense of meaning in life and be at peace with

themselves and significant others than being active or physically comfortable. As recommended by the authors, it is therefore important to assess, identify and address the psychological and spiritual care needs of patients and support them in adjusting to their functional limitations (Selwyn, 2005; USAID 2009; Selman et al, 2011).

5.5.2 Educational and professional recommendations:

In the current study, AIDS patients were so common in the palliative wards that they were perceived as “just as another condition,” which impacted negatively on the participants as they felt it impeded their academic and professional growth. According to Selman et al., (2011:12), *“The heterogeneity of patient experiences should be taken into account by ensuring that multidimensional needs are assessed regularly and that care is patient-centered and tailored to individual patient and family needs.”* Other researchers in palliative care settings have identified the urgent need for professionals to be supported through training and guidance, in order to improve patient outcomes (USAID, 2009; Bausewein et al, 2011). Nursing need not only focus at achieving and maintaining health, but on ensuring that those who are facing death can live comfortably and die in dignity (Nursing Act, 2005).

5.5.3 Managerial and policy recommendations:

Both the Nursing Strategy for South Africa, (2008) and the nurses who participated in the current study, echoed that specific focus should be placed on the improvement of quality health care in all health sectors, but that it is a major priority in the public sector. To achieve this, good leadership at all levels, from the basic categories to the policy formulating professionals, is critical to facilitate and direct the education and training of nurses. Strengthening the professionalism of nurses and the provision of

practice related resources are the key drivers that support the needs of the dynamic health care system at its micro and macro-systemic levels (Nursing Strategy, for SA, 2008). Lack of management skills has been identified as one of the key barriers to achieving the health-related goals, and in order to address this deficiency people management; self-management competencies; and task-related skills are vital requirements for both private and public hospitals (Pillay, 2010).

It is suggested that nurses caring for terminally ill patients with AIDS should be compensated accordingly by means of an extra allowance. This idea is supported by, findings of Mulaudzi et al, (2011), whereby over half of the nurses felt that an extra allowance was necessary due to the prolonged nursing care activities the nurses dealt with.

5.5.4 Research Recommendations

The researcher recommends that the following research would be of benefit to the nursing profession:

- An exploratory study to identify nurses infected with HIV/AIDS and to explore how their care impact on patients infected with HIV/AIDS.
- A comparative study to identify quality care from the patients' perspectives in private and public hospitals.
- To explore quality of life among patients receiving palliative care in Sub-Saharan Africa and Europe.
- The research has noted that oncology settings and palliative contexts are comparable in terms of emotional issues experienced by the nurses. An exploratory study to explore the experiences of patients in these settings would enhance understanding of patient-related issues.

5.6 CONCLUSION

Due to increased nursing work-load in the context of HIV/AIDS (van Rooyen et al, 2009), particularly in the care of terminally ill patients dying of AIDS in palliative care contexts, nurses deal with complex and demanding emotional issues (Kell and Walley, 2009) of patients threatened by AIDS, a life-limiting disease requiring special care needs (Tapsfield and Bates, 2011). In the findings of the current study, nurses admit that they feel overwhelmed by the increasing number of terminally ill patients admitted into the palliative wards, who tend to suffer from complications of the disease and need more time consuming and prolonged care than other patients (Cullinan, 2006, Mulaudzi et al, 2011). Consequently, the participants experienced symptoms such as fatigue, due to prolonged contact with dying patients (Smit, 2005) and became emotionally and spiritually drained through the continual exposure to suffering (van Rooyen et al, 2009).

However, training activities that include management of opportunistic infections, adherence counseling and bereavement courses were opportunities for learning for the nurses within palliative care contexts, and kept them motivated to respond to the escalating burden of diseases in ever changing public health needs (Zachariah et al, 2008). The nurses in the current study integrated other internal resources such as praying to God and a genuine love of their patients into their work, thus making the experience of caring for terminal patients with AIDS less stressful, as their faith gave them strength to cope (van Rooyen et al, 2009) and they achieved quality palliative outcomes for the mutual benefit of their patients and themselves.

On the other hand, the participants stated that routine exposure to death and dying accustoms the nurses to dealing with death, leading to situations where they display

lack of care and respect for the dead. This was particularly noted in some of the younger nurses, who, giggled or chatted while handling the corpse or transporting it to the mortuary. It was also explained by the nurses that antecedents such as the nurses' backgrounds should also be taken into account as painful events of abuse or personal infection with HIV may have a negative influence on the care they render, thus impeding effective and efficient service delivery in palliative care contexts.

Therefore, in support of nurses working in emotionally taxing contexts, such as the palliative care wards, the emotional antecedents that alter the personal levels of caring are an agenda that need to be addressed in order to achieve improved nurse-patient relationships that will ultimately enhance the provision of quality palliative care within the organization and the nursing profession as a whole (Pisaniello et al, 2012). Leaders are encouraged to be supportive and facilitate behaviors that stimulate interest in the work place, encourage awareness of problems and strengthen the nurses' abilities to think and resolve them creatively (Rafferty and Griffin, 2004), so as to continue improving the quality care for terminal patients (Selman et al, 2011).

Facilitation of emotional antecedents can also be achieved by the nurses, themselves, through self-reflection exercises and being open to informative feedback on their actions so that wholeness can be achieved for the well-being of the nurses and their patients, and that balanced holistic nursing can be maintained (Anthony and Barkell, 2008; McEvoy and Duffy 2008), in palliative care settings for patients with AIDS.

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7.1 APPENDIX ONE

INFORMATION DOCUMENT

Object: Invitation to participate in a research study

Dear Participant,

I am studying at the School of Nursing at the University of KwaZulu-Natal. I am carrying out a research study on: “Exploring the lived experiences of nurses caring for terminally ill patients with AIDS in selected wards in a level 1 District Hospital in KwaZulu Natal.”

The aim The aim of this study is to explore and the lived experiences of nurses caring for patients dying of HIV/AIDS.

Invitation to participate: I am inviting you to participate in this study by filling in the attached questionnaire. Participation is voluntary; you can withdraw without any punitive consequences, if you want to do so. Your collaboration in this exercise is very important in the accomplishment of our study objectives.

Risk: Participating in this research may never lead you to any risk or harm, only it may inconvenience you in terms of time to complete the questionnaire.

Benefits: There wouldn't be immediate benefits to the participant from this study; however the findings from this study will help the relevant authorities at the Hospitals and the school of nursing to improve policy and curriculum to ensure quality care and staff satisfaction.

Confidentiality: The information obtained from you will be kept to the highest possible level of confidentiality. The anonymous questionnaire will be used to collect data, and it is guaranteed that there won't be any link of data to one's identification during data collection, data analysis, and dissemination of findings. Before and during data analysis, questionnaires will be kept in a locked cupboard where only the researcher has access. After the project has come to completion, questionnaires will be destroyed by burning.

N.B: By completing this questionnaire, you will have consented to participate in the study and should you so require, the findings of this study will be communicated to you.

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Consent Form:

I----- (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am free to withdraw from the project at any time, should I so desire.

Signature of participant:

Signature of Witness:

Date:

7.2 APPENDIX TWO (SECTION A)

Section A

Demographic Data

Please answer to the following questions and indicate with a tick (✓) where applicable.

Part I. Participant identification

1. Gender..... Male Female

2. Age.....

3. Highest Standard Passed at School

Primary
Secondary
Tertiary
Professional

4. Religion:

Roman Catholic	Protestant	Shembe	Other (please specify)

6. Race :(For statistics purposes)

Black	Indian	Colored	White

7. Marital Status:

Single	Married	Divorced	Widowed	Cohabiting(living	Other

				together)	

8. The position or role of the participant:

- 1. Professional nurse.....
- 2. Enrolled nurse.....
- 3. Enrolled nurse Assistant.....
- 4. Years of experience in terminal patient care...

9. Ward in which you work in: Male ward female ward

10. Years of experience, in clinical area:
- 1. 1-2 years.....
 - 2. 2-3 years.....
 - 3. 3-4 years.....
 - Any other, Please indicate 4.....

7.3 APPENDIX THREE (SECTION B)

Section B

Part II. Interview Guide:

The interview guide consists of open-ended questions which will be employed during the individual interviews. The questions below will aid realization of the objectives as shown in the data collection procedure. They will be supplemented with probes to facilitate and steer the conversations with the participants.

Setting the scene:

Ensure private venue for the interview.

Establish rapport: greet the participants, thank the interviewee for permission given to be interviewed.

Give an overview of the study and provide a brief summary of its objectives.

Discuss issues of confidentiality, voluntary participation and illustrated in the information document. (Refer appendix one). Obtain written consent.

Allow participants to choose pseudo-names or the letters of the alphabet they would like to be used throughout the interview process. Before turning on the tape recorder, explain to the interviewees that recording helps prevent distractions caused by note writing and ensures that essence of information is captured.

This is a semi-structured interview. It is important to begin with less threatening and broad questions such as, "Can you please tell me about your experiences of caring for HIV/AIDS patients?" Thereafter the cues illustrated below, will guide the researcher, during the process of interview. It is hoped that the following cues will facilitate realization of the three main research questions. They are as follows:

1. Tell me more about your experiences for caring.
2. What do they mean for you?

3. What does the concept of caring and terminally ill mean for you?
4. From the experiences you have shared, can you tell me how this affects your nursing
5. Describe this experience?
6. What would you change in your practice?

Finally, thank the interviewees for their time and participation. Allow time for questions and additions to the interview. Schedule a follow-up interview to clarify and check information obtained in the interview process.

7.4 APPENDIX FOUR

Bracketing (Phenomenological Reduction) of Researcher Presuppositions:

The researcher first considered her own preconceptions about the phenomena under study, wrote them down and attempted to put them aside. Phenomenological Reduction is necessary to avoid any “researcher bias” effects from influencing the data analysis process and reporting of the results of the study.

Caring for Terminally ill patients with AIDS.

I believe that caring is central and a natural act to the nurses. This is clearly expressed in a certain authors' words, thus, “Nurses give care without prescription.” The nurses are usually identified in terms of how caring or uncaring they are. I think that an environment that enables nurses to express positive caring attitudes is that in which managerial support is visible through:

Consultative forums which represent the interests of nurses in the workplace, e.g. appropriate unions.

Training and education: broadens one horizon and enables one to keep up-to-date knowledge, and prevents rigid workplace practices & burnout.

Failure to provide such an environment, results in impaired care, shown by verbal abuse of colleagues and patients, demeaning jokes, gossips and passive resistance of employees.

On confronting death of terminal patients:

I was always struck by the strong emotions that I felt within me. I had a sense of hopelessness and sadness that I felt for the dying patients and their families/relatives who would now have to cope with the loss of a loved one. After spending over two years in an outpatient department, (whereby death of young & old with AIDS had become a daily reality) I felt that I was gradually losing interest in nursing. I often caught myself being impatient towards the patients/public, and staff.

Such an exposure had some effects on some staff members as well. Some staff members verbalized how tense & stressed they were & attributed this to the fact that they dealt with deaths at the workplace & homes/community, often without support or appreciation but with piling complaints from management and the public.

What kept me going in such a tough situation was an avenue to share my stressful experiences with someone outside the work-place, such as, spiritual director and also an opportunity to further up my studies through a university.

14 May 2010

Ms N Bam
St Mary's Hospital
P O Box 10405
ASHWOOD
3605

Dear Ms Bam

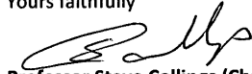
PROTOCOL: Exploring the lived experiences of nurses caring for terminally ill patients living with AIDS, in selected wards in a level 1 district hospital in KwaZulu Natal
ETHICAL APPROVAL NUMBER: HSS/0234/2010 H: Faculty of Health Sciences

In response to your application dated 12 May 2010, Student Number: **205509475** the Humanities & Social Sciences Ethics Committee has considered the abovementioned application and the protocol has been given **FULL APPROVAL**.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully



Professor Steve Collings (Chair)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

SC/sn

cc: J Naidoo
cc: S Reddy

7.6 APPENDIX SIX



ST. MARY'S HOSPITAL

MARIANNAHILL

St. Mary's Hospital
P/Bag X 16
ASHWOOD
3605
29.04.10

Chief Executive Officer
St. Mary's Hospital
Mariannahill

Request to conduct a research project at St Mary's Hospital

Dear Dr. Ross,

My name Nokwanda Bam. I am a postgraduate student at the University of KwaZulu-Natal. I am a Master's Degree - Course Work, in Nursing Management. My dissertation is being undertaken as partial fulfillment of the requirements for this degree.

The title of the research project is:

“Exploring the lived experiences of nurses caring for terminally ill patients living with AIDS in selected wards in a level 1 District hospital in KwaZulu Natal.”

The aim of the study is to explore and describe the lived experiences of nurses caring for terminal patients living with AIDS.

Permission to conduct the study will be obtained from the University of KwaZulu Natal, Ethics Committee.

No costs would be incurred by the hospital during the data collection phase. Participating staff members would be asked to do so at a time that is convenient to both the hospital and the staff members concerned. The benefit of the study to the hospital would be primarily in terms of the results obtained- and how these could be applied by the middle and senior hospital management in quality improvement in the palliative care wards.

My research supervisor is Joanne Rachel Naidoo, for any queries she can be reached on the contact details below:

Research Project Manager
School of Nursing
University of KwaZulu - Natal
Tel: +27 31 260 22 13
Fax. No: +27 31 260 15 43
E-mail: kistenjr@ukzn.ac.za Fax: +27(0)31 260 1543

A one page response from you will be appreciated.
Hoping that this request will receive your favorable consideration. Thanking you in anticipation.

Nokwanda Bam

7.7 APPENDIX SEVEN

TRANSCRIPT OF REGISTERED NURSE: ALICE

STUDY SETTING: ST. MARY'S HOSPITAL

DATE: 17.06.10

VENUE: OFFICE OF THE PARTICIPANT

TIME: 13H00

Interviewer: thank you very much Alice for the time you have given to be a participant in the study. I know you have enough in your plate, particularly now that you have given your lunch time and made yourself available for the interview.

About Term Caring: What's your understanding Alice?

Interviewee: (Rolling her eyes)... well I believe that caring is essential in nursing. My understanding is we should be showing how to care for our patients, by communicating well with them. By accepting them Having non-judgmental attitudes towards them...empathizing with them...showing all our listening skills for example we should be draw into a trust relationship with us...I think that that really is the basis of caring...

Interviewer: About the term, Terminal Patient: what is it for you?

Interviewee: Terminal patient is one who has probably poor prognosis. Probably, in the last stages of life.....Maybe approaching death soon or may have a few weeks/ months period of life....nothing can be done for patient....the only thing to assist in pain control....

Interviewer:

You said, you worked with male female patients, what was your experience?

Interviewee:

Well, that was a long time ago.... I worked a lot with the care of the elderly....from 1996-2000 I worked in (mentions the name of Hospital) which specialized in chronic ill patients....and the terminal ill patients....It all began in 2008 when I was in a surgical ward.....We had a patient who came in for exploration and he had a small incision but it never healed. Two months to three months down the line the whole abdominal normal wall had broken down. She was an amazing patient...Her family visited. I was just there, comforting them...counseling them...There are many, many terminally ill patients I nursed, mainly with HIV/AIDS, a few cancer cases and other chronic disease such hypertension and Diabetes Mellitus. All were hospital based of cause.

Interviewer: What helped you to care for your patients?

Interviewee: My own background helped me a lot. I come from a caring family....the marvelous role models I had when I was on training. They were totally professional

people and they showed compassion...and dedication. Responsibility in caring for them: as a senior nurse I was in-charge of the ward...and I had to take responsibility for caring for those people, which I actually quite enjoyed.

Interviewer: What hindered you from caring for your patients that were terminally ill?

Interviewee: Burnout is one major hindrance of them: When you just can't face to look at another terminally patient. With it you get very tired...and then you giving of yourself all the time,..you are so exhausted that you can't anymore give of yourself. I think that it's a big problem, in terminally ill....in fact in any nursing actually you do get burnout.

Management: When you have got a terminally patient and you are called away from the ward, because of the meeting or they want something from you to do....where you have to leave the ward....but you have a patient that is probably demise for the next 20 minutes...you can incur the wrath of management if you say no, I am not coming...as one manager couldn't no longer talk to me when I said I couldn't live a patient a lone.

But I think burnout is the most terrible experience in nursing.

Ummm, what else? Patients that are terminally ill for long time...

Shortage of staff, you cannot actually spend the time you want to spend with the patient...you feel limited in many ways.

Emmm, what else...patients that are ill for a long, in the long run you get tired....

Interviewer:

How did your experiences influence the care that you give to your patients?

Interviewee: Actually having lengthy experiences in nursing it's wonderful. It makes you more relaxed in caring for your patients. You have experience in caring for a relative...What else...or another thing, which helps to care for patients is support: if you have a good team, it's actually marvelous. If you don't have this it's not easy...because we help one another in the care of terminally ill patients. If you don't have that then...it's not easy unless you have a team.

Experience is important because it makes you more relaxed and more able to handle the situations. Sometimes we have to help patient to finish unfinished business...and you know,,,I think as a young sister I would not have known what to do...but as I matured and became more experienced, I was able to cope better too.

Interviewer: What would you improve on for the care of terminal patients?

Interviewee: Understanding of terminally and palliative care:

Clinically on the ward, if the patient is in charge, it must be more someone who is a role model...good role model for the students to emulate..Emm, I am just thinking now of the situation in (mentions name of hospital)...we had a very close network system...we all supported one another and helped one another, sometimes if you saw something which was too much for one, we all came around and helped. The one sister would just call and ask for assistance, please come and help, I have a problem here...and we would respond...so that team work was absolutely wonderful. And of course we also laughed. We had a lovely tea lounge, we used to sit and used to...laugh at ourselves at our predicaments and the various things that happened at

the hosp. so that was absolutely wonderful and those people I was working with, we had such a bond...so it's important to create unity with the staff. They bond.. they connect with each other....so when one is tired the other will step in....But I don't know where is that support and networking in nursing today... we seem to have lost such a precious time...When I look back on it, and think what a wonderful time! If you want to discuss something, say you are worried about pain –control, then you know you felt comfortable calling another member of staff and saying, there is this patient with pain, what do you suggest to do with this?

They are wonderful support:

We had times too: e.g. nurse with nervous breakdown: we all supported her, trying to get her back to work.

So thanks it was great to have you for an interview.

I hope I said the right thing, and everything.

Interviewer: Thank you Alice very much for sharing your rich experience with me.

If I there is anything, that I need clarity on, once I have transcribed your information, I will contact for clarification. I hope you do not mind.

Interviewee: Oh no please, feel free.

The interview ended at 13:45

7.8 APPENDIX EIGHT

FIELD NOTES – ALICE (REGISTERED NURSE)

STUDY SETTING: ST. MARY'S HOSPITAL

DATE: 17.06.10

VENUE: OFFICE OF THE PARTICIPANT

TIME: 13H00-13h45

GENDER: FEMALE

RACE: WHITE

AGE: 62

Years of experience in nursing 25 years

Participant criteria:

1. Category of nursing: YES
2. At least a year in palliative wards: YES
3. Willing to participate: YES

After completing the Demographic data, the participant signed the consent.

Thereafter she chose a pseudo-name, as Alice. The participant was a very mature woman who spoke English fluently. She was at ease with the interview process, calm and thinking individual. This was conveyed throughout the interview, maintaining appropriate body language with open body posture, good eye contact forward leaning occasionally and leaning back in a relaxed position.

Once the tape was off, she spoke at length about one of her patients who had TB and HIV/AIDS. Many nurses avoided the man due to his excessive cough. She would assist the patient during her team with mouth care, feed him and feed him. The patient responded that "I trust you; I am still alive because of you."

She explained that one of the reasons, people did not like the patient is that when coughing he would not close his mouth, and when advised to close the mouth, he would take offence and shout at the nurses. In the end after efforts and patience with him, he understood why he had to wear the mask, in order to protect other patients and the nurses caring for him. Eventually he was discharged home, and happy with his fellow patients, nurses and particularly Alice. They exchanged phone numbers so that when he needed help with his treatment or problems encountered he could call and get the assistance whenever needed. Alice was very happy relating this story as one among many of her success stories of patients who recovered, from a critical stage to full recovery on antiretroviral treatment.

Alice was thanked for her openness and willingness to be interviewed.
Interview ended at 13H30.

7.9 APPENDIX NINE

Gender

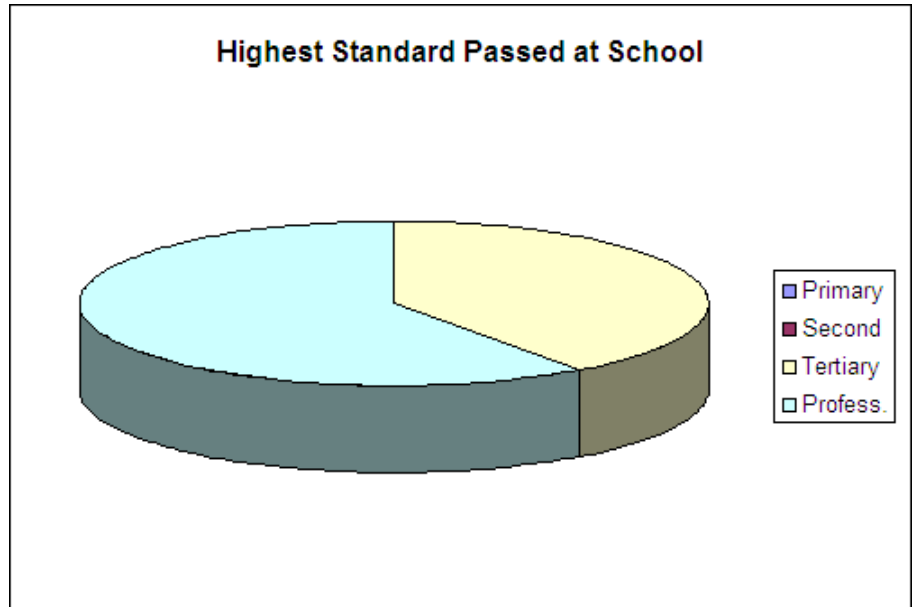
Male	1	10.0%
Female	9	90.0%
Cases	10	

Age

21-30	6	60.0%
31-40	2	20.0%
41-50	0	0.0%
51-60	0	0.0%
>60	2	20.0%
Cases	10	

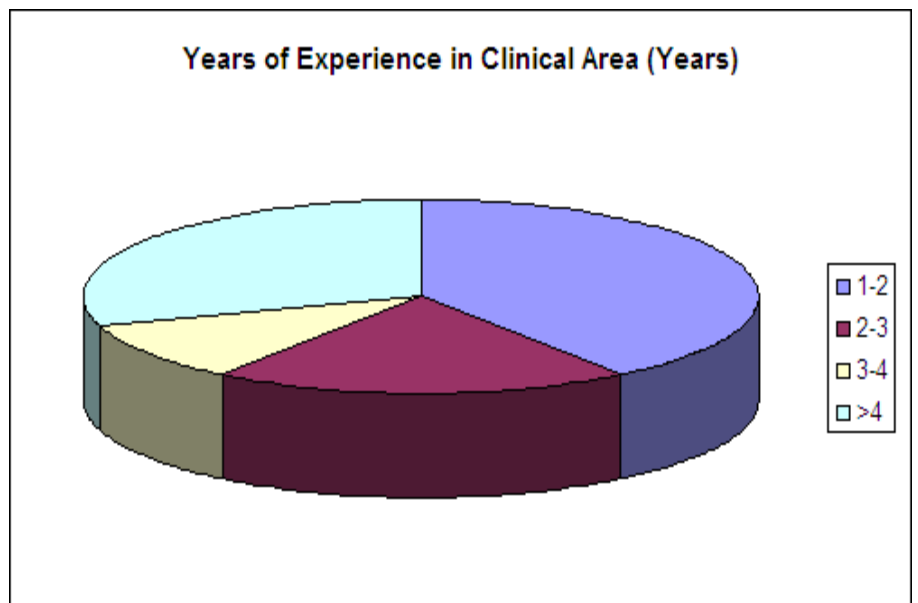
School

Primary	0	0.0%
Second	0	0.0%
Tertiary	4	40.0%
Profess.	6	60.0%
Cases	10	



Exp Clin.

1-2	4	40.0%
2-3	2	20.0%
3-4	1	10.0%
>4	3	30.0%
Cases	10	



7.10 APPENDIX TEN

Table 3.5 Appendix 7.10: Giorgis Steps of analysis

Step One: Read to get sense of the whole

P1 Nandi	P2 SM	P3 R/N B	P4 Charon	P5 Dineo	P6 Bear	P7 Bony	P8 Tholoana	P9 Sr. V	P10 Alice
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Meaning Units from each of participants scripts on the essence of phenomenon (Experiences of Nurses caring for terminal AIDS patients): step Two

Holistic care, Based on past experiences, AIDS is an Opportunity, God helps to care & resources, Awareness of own death	Sick mum, To help, To be the mind of pt. Hard to recovery, Faith helps to care, Peaceful death, Fear of infection, Limiting,	Holistic Care, Given to helpless Pts. How much could I have done?	Total care, Sacrifice time, To care started with my sister. Criticism blocks care, Towards death,	Nursing of sick, Hard to care, Pts annoy, Talking with pts helps to care, Dying pt.	Take care of pts & their belongings, tough to care, involves ethical dilemma All pts with incurable disease need care,	To love, to put self in some else's shoes. Not an easy thing, But prayer helps & resources, Need MDTeam Terminal pts may live longer.	To love, Very ill & dependent pts, prayer helps me to best care	The sick need care, Pt with incurable disease terminal care.	-caring is essential Demons -trated by listening -Fosters trust -poor prognosis -last stage of life -nothing can be done for terminal ill pts, burnout if prolonged
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Examining and relating meaning Units to each other: Step Three

- 6 Meaning units have been grouped/related to each other. As identified with different colors they are:
1. Definition of the concept: (value, essential, core to nursing)
 2. Care Activities: (Demonstrated by, listening, love, putting yourself in other's shoes, be the mind of patient, total, sacrifice, all encompassing).
 3. Caring is experienced as an encounter: (changes with diseases, begins at home, Aids is an opportunity).
 4. Challenges related to care: (fear of infection, criticisms, annoying patients, (these limit care, as it becomes hard uneasy).
 5. Characteristics inherent in care: (God as provider of protection, resources minimize tension, communication and support (in the MDT, & Patients).
 6. In terminal care: (**defined** as poor prognosis, hard to recover, ill & dependent need to be assisted with peaceful

death, they are in their last stages of life but some may live longer), (**interventions** nothing can be done to them, making care to be monotonous), Helps to think about own death.

Redundancies (repeated words): (holistic care/total MDTeam embedded), care as loving, sick need care, patient with incurable disease,)

Step Three:

Can further be re-grouped as :

1. Definitions: Numbers 1& 6
2. Experiences of care: brown colored

Step four: Transformations of the daily expressions into psychological language (Refer Chapter four)

Step five: formalizing a consistent description of the structure of the phenomenon under study across subjects, (Refer Chapter five).

7.11 APPENDIX ELEVEN

Description of the participants

<u>Pseudonym chosen</u> <u>By each</u> <u>participant</u>	<u>Number of</u> <u>interviews</u>	<u>Experience in</u> <u>the care of</u> <u>terminal patients</u>	<u>Brief background</u> <u>about the</u> <u>participants</u>
1. Nandi	One	Twenty two years	She is 62 years; she is a R/N and a unit manager for the male/female wards.
2. Sweet Melody	Two	One year	She is 26 years, a Roman Catholic religious sister. She is an enrolled assistant nurse. Has one year of experience and is continuing her studies for enrolment as an enrolled nurse.
3. SR. B (RN B)	One	Four years	She is 34 years old. A religious sister, with experience both in male and female wards.
4. Charon (STN C)	Two	Two years	A 24 years enrolled nurse. She is single. She is a Christian. Had a follow-up interview for clarity.
5. Dineo	One	One year	She is a 23 years, enrolled nurse assistant. Continuing

			her studies to be an enrolled nurse.
6. Bear	One	Two years	She is 24 years old. She is an enrolled nurse and is single. Has completed a 6/12 palliative course.
7. Tholoana	One	Three years	She is a 30 years old enrolled nurse. Has experience both in male and female wards.
8. Sr. V	One	Seven years	She is 36 years old and is single. She is a R/N with experience both in male/female wards.
9. Bony	One	Two years	He is a 27 years old male who is single. He is R/N with experience both in male/female wards.
10. Sr. Alice	One	Twenty years	She is a 62 years old female and is married. She has experience in male and female wards.

7.12 APPENDIX TWELVE

Editing Declaration

P O Box 531
Hillcrest
3650
KwaZulu-Natal

2012-07-03

TO WHOM IT MAY CONCERN

Thesis Title: EXPLORING THE LIVED EXPERIENCES OF NURSES CARING FOR TERMINALLY ILL PATIENTS WITH AIDS IN SELECTED WARDS IN A LEVEL 1 DISTRICT HOSPITAL IN KWAZULU-NATAL

Author: Nokwanda Bam

This is to certify that I have edited the above thesis from an English language perspective only, and have made recommendations to the author regarding spelling, grammar, punctuation, structure and general presentation.

A marked-up version of the thesis has been sent to the author and is available as proof of editing.

I have had no input with regard to the technical content of the document and have no control over the final version of the thesis as it is the prerogative of the student to either accept or reject any recommendations I have made.

Therefore, I accept no responsibility for the final assessment of the document

Yours faithfully



Margaret Addis