THE DEVELOPMENT OF PALLIATIVE CARE PROTOCOLS FOR THE EMERGENCY AND ONCOLOGY NURSES IN THE GOVERNMENT HOSPITALS OF THE WESTERN CAPE

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A dissertation submitted in fulfilment of the requirements for the degree:

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10 January 2019

DECLARATION

I declare that "**The development of palliative care protocols for Emergency and Oncology Nurses in the government hospitals of the Western Cape**," is my own work, that it has not been submitted for any other degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

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DEDICATION

To my late father, Kenneth Smith, for encouraging me in my endeavours and for always being steadfast in believing in me.

To my husband, Brian February, the wind beneath my wings, without you this would not have been possible.

I also dedicate this work to my loving son, Christopher Albert.

To the late Tanya Van Lilly—this research is in memory of you.

QUOTATION

However long the night, the dawn will break.

African Proverb

ACKNOWLEDGEMENTS

I give thanks and praise to our Heavenly Redeemer for giving me the gift of grace to accomplish my educational pursuit.

- To my mother, Gwen Smith, for laying the foundation of nursing in encouraging me to be a nurse and for supporting me, thank you.
- To my one and only Christopher, my child, you have been accommodating and sacrificed so much in allowing me to complete my dream, thank you.
- To my sister Georgia Smith Clayton, thank you for being supportive throughout my nursing research journey.
- To my supervisor Dr Sathasivan Arunachallam, and co-supervisor Professor Jennifer Chipps, thank you for your guidance.
- To Christine Nachman, your inspiration and guidance was invaluable.
- To my friend, Patricia Overmeyer, thank you for keeping me motivated.
- To my research coach, Ahmed Eldud, for always availing yourself.
- To the management and my colleagues of Western Cape College of Nursing, thank you for your support.
- To the Oncology Patients and their families, for allowing me to gain insight into your lives. I am humbled.
- The Nursing Management and Nursing Staff of Groote Schuur, Tygerberg and Victoria Hospitals, for their invaluable contribution towards my study.

- To Professor Donavon Hiss, your mentorship and direction towards the final part of my thesis is a light at the end of a long tunnel. Thank you.

ABSTRACT

Background: Palliative care is specialised health care to support people living with a terminal illness, and their families. Palliative care aims to prevent and relieve suffering, to help people to live as well as possible until they die, and to support the processes of dying and bereavement. Palliative care is holistic care provided by Emergency and Oncology Nurses caring for cancer patients. Palliative care protocols for Professional Nurses working in Emergency Units and Oncology Departments are not always posted or in full view in the government hospitals of the Western Cape. The researcher had noted that the development of a palliative care protocol would be unique in its use at the three targeted government hospitals.

Aims and Objectives: This study focused on the development and implementation of palliative care protocols for Emergency and Oncology Nurses in the targeted government hospitals of the Western Cape, i.e., protocols could be beneficial for cancer patients and their families. The overall aim of the research was to develop applied palliative care protocols for Emergency and Oncology Nurses to provide best practice palliative care nursing for Oncology Patients who may present at any one of three Western Cape Provincial Hospitals.

Methods: The research design was a mixed method. The primary targets of investigation were the knowledge, attitudes, practices and experience of Emergency Professional Nurses and Oncology Nurses, regarding palliative care protocols. In addition, the research encompassed an investigation of the knowledge, attitudes and experience, of the patients and their families regarding palliative care protocols. The admission process of the cancer patient was traced from Admissions to Emergency Departments, then to the Oncology Department. The sample consisted of 57 Emergency and Oncology Nurses working in the Emergency and Oncology Departments of the government hospitals selected for this study. A purposive sampling technique to select Emergency and Oncology Nurses was applied, and data collection involved the use of questionnaires, a palliative quiz and unstructured in-depth individual interviews, and focus group discussions. The cancer patients and their families included in the research were 25 participants interviewed at the participating Western Cape government hospitals. Thematic analysis was done through the process of coding in six phases to create established and meaningful patterns. These phases were familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report.

Results: A total of 3 themes and 12 sub-themes emerged from the unstructured interviews and focus group discussion. Central to the data analysis process were the palliative care protocols that were formulated. The researcher achieved this by engaging with the professional emergency oncology and emergency nursing staff, the patients and the patients' families. Concepts were validated and guidelines for protocol development were drawn up. The researcher engaged with the patients and the patients' family from admission at the Emergency Department to the transfer and continuation of care in the Oncology Department, and followed-up at the Out-Patient Oncology Department. Limitations were identified and recommendations for nursing practice, education and further research concluded the study.

Conclusion: A palliative care protocol can be supported in palliative care delivery in the government hospitals by involving the Emergency Nurse and Oncology Nurse as per admission process. The empowerment of Oncology Patients and their families in decision-making and consulting opportunities will promote ownership, accountability and sustainability of the protocol. The knowledge and practices, including the experience of the Professional Nurses working in the Emergency and Oncology Departments will be adjusted and regulated, and this in turn will inspire greater trust and confidence in the delivery of palliative care. The findings of the research ultimately revealed that palliative care must address total pain and suffering. Widely accessible, attainable and effective analgesia is a great-unmet need in Africa and Sub-Saharan Africa, and morphine supplies are alarmingly insufficient. For palliative care to be accessible, attainable, effective and sustainable, it must be integrated and prioritised into mainstream services such as government hospitals, alongside curative and preventative care. Palliative care is possible in

resource poor settings, by building on community capital, acknowledging patients' pronounced physical, psychosocial, emotional and spiritual needs, and to providing psychological and spiritual support to the patient and their family from the admission, and this includes bereavement support for the family. The results of the study further provide detailed information about the palliative care patient and family experience. The study also demonstrates the important role of palliative care in the hospital. Emergency and Oncology Nurses need adequate resources and knowledge about symptom management and palliative care, in order to provide good care to these cancer patients during their hospital stay. In addition, early integration of palliative care in the Emergency Department may optimize the quality of care rendered.

Recommendations: In this study, based on scrutiny of questionnaire results, recommendations for nursing practice, nursing education and nursing research were formulated. According to the majority of nurses in both Emergency and Oncology Units, the single most important factor contributing to patient-centered care is the commitment and engagement of senior management. In order to accomplish the main priorities for nursing practice, managers should be dedicated and have a clear vision and strategic plan for the prioritization of palliative care and its daily use. In addition, organizational transformation is required to achieve the sustained delivery of patient-centered palliative care. The main recommendations for nursing education almost certainly implicate education and shared knowledge; respect for patient-centered values, preferences and expressed needs; coordination and integration of care across clinical, ancillary and support services; information, communication and education on clinical status; physical comfort and pain management; emotional support and alleviation of fear and anxiety; involvement of the family in decision-making, transition, continuity and information to promote patients self-care; access to care; focus on cognitive and behavioral dimension of pain and symptoms; intervention for effective training of health professionals, patients and families as care givers and improved bereavement outreach, focusing on the family. The South African Department of Higher Education should navigate the integration of palliative care into the medical and the nursing curricula, and urge nurses to develop specialized tracks in this field. Masters and specialized programs should

also be offered by South African universities to enhance the qualification of the health care professionals and to stimulate research in palliative care. The researcher hopes that this study will broaden the knowledge and reflection on the substantive needs of family caregivers in the hospital context. There is thus a need to develop further research in this field and involve a larger number of families.

Keywords: death anxiety, emergency unit, family member, oncology environment, oncology experience, palliative care protocol

LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
APCA	African Palliative Care Association
DOH	Department of Health
EBSCO	Elton Bryson Stephens Company Information Services (ebscohost.com)
EOL	End-of-life
CANSA	Cancer Association of South Africa
CINAHL	Cumulative Index to Nursing and Allied Health Literature
ED	Emergency Department
EOL	End-of-Life
FATCOD	Frommelt Attitudes Toward Care of the Dying
FGD	Focus Group Discussion
GSH	Groote Schuur Hospital
HIV	Human Immunodefiency Virus
HPCA	Hospice Palliative Care Association of South Africa
ISQua	International Society for Quality in Health Care
KAP	Knowledge, Attitudes and Practices
MOU	Memorandum of Understanding
OPD	Out-Patients Department
PC	Palliative Care
PCC	Patient-Centred Care
PFCP	Patient-and Family-Centered Care Protocol
PPC	Protocol Palliative Care
QOL	Quality-of-Life
QOC	Quality-of-Care
SANC	South African Nursing Council
SSA	Sub-Saharan Africa
TBH	Tygerberg Hospital
VH	Victoria Hospital
WHO	World Health Organisation

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 Introduction

The World Health Organisation (WHO) defines palliative care as an approach that improves the Quality-of-Life (QOL) of clients and their families facing life-threatening illness (WHO, 2009). Globally, it is estimated that 20 million patients or more need palliative care at the End-of-Life (EOL) and this number doubles if we include those patients at earlier stages of illness who could also benefit from such care. Nevertheless, only 3 million EOL patients receive palliative care; most global palliative services are found in developed countries, while 80% of the need for this care globally is in low-and middle-income countries.

The science of palliative care has undergone rapid development since the last decade, most notably with advances in the pharmacological interventions to relieve chronic pain. In South Africa, the situation regarding palliative care is that approximately 80% of Oncology Patients are presenting with advanced incurable progressive disease (Freund, Battaglia, Calhoun, Dudley, Fiscella, Paskett, & Roetzheim, 2008:3391-3399). The current statistics of the Cancer Association reveal an increase in newly diagnosed cancer cases and show that cancer is one of the leading causes of death in South Africa. Cancer, according to Maree (2007:887), has an intense effect on the physical, psychological, social and spiritual aspects of life because of its often linked with suffering and death.

Palliative care differs substantially from hospice care, in that hospice care focuses on the end stages, when the patient is terminal with advanced cancer, whereas palliative care commences from the onset of diagnosis to disease progression and finally to EOL care, including family bereavement. Palliative care is provided through comprehensive management of the physical, psychological, social and spiritual needs of Oncology Patients while remaining sensitive to their personal, cultural, and religious values and beliefs. A study undertaken by Varga & Paulus (2014:443-449) aimed to understand the preferences for outcomes and risks involved in treatment. The emphasis of the research was to highlight the palliative patient’s needs understood holistically, and the role of the family in improving the QOL of the patient and in relieving the pain and suffering of the patient. The application of palliative care protocols, as highlighted by Costello (2006:594-601), is not an alternative to other care, but something that is a complementary and essential component of holistic total patient care. Literature shows that palliative care protocols do affect directly on the Oncology Patients with life-limiting illness that often experience significant suffering early in the course of the disease (Costello, 2006:94-601).

Feldstein & Gemma (1995:85-236) stated that many Emergency and Oncology Nurses need palliative care protocols that would enable them to manage the patient and the family within the organisation, and also provide insight into palliative care from the outset when the patient is admitted. The integration of palliative care into the continuum of care, within the oncology hospitals of the provincial health sector, would need the involvement of the Professional Nurse (Harding, 2012:45). According to Feldstein & Gemma (1995:85-236), Emergency and Oncology Nurses need to be prepared from the start, with the Oncology Patient’s admission to hospital in the Emergency Department.

1.2 Problem Statement

In the Western Cape provincial hospitals there is very little evidence of applied palliative protocols guiding the admission and management of Oncology Patients as they move through the hospital system. Lack of use of protocols negatively affects the provision of quality palliative care. The problem is further intensified for the Oncology Patient and their family members who accompany them to the hospital, with no palliative protocol to assist them whilst in the hospital or at home. Internationally, the science of palliative care has undergone rapid development, most notably with advances in the pharmacological interventions to relieve chronic pain. The family members are the caregivers who provide support to the oncology patient, the family member experiences distress, feelings of burden and decreased quality of life as a result of caregiving, (Wittenberg, Goldsmith, Williams & Lee:2018) . The quality of communication between the oncology patient and the family member, as caregiver affects the quality of life and well- being for the two; however the family member may need more support from the nurses. The family members as caregivers often turn to the nurses for support; however, there is minimal resources of training available for the nurses in how to care for the family caregiver.

In South Africa, Emergency and Oncology Nurses are in a unique situation as the carers and direct managers of the health care system on a 24-hour basis. The Emergency and Oncology Nurses should examine how to support the family member in learning how to develop effective communication strategies, (Wittenberg *et al*: 2018) Furthermore, these Emergency and Oncology Nurses, according to their scope of practice, have the authority to incorporate and to develop the principles and practice of palliative care standard operating procedures into their daily work where it is appropriate to do so. . The values that underpin high quality palliative care are integral to good professional nursing (Feldstein & Gemma, 1995:234).

According to Feldstein & Gemma (1995:234), many Emergency and Oncology Nurses do require palliative care standard operating procedures that will enable them to manage the patient and the family within the organisation, with insight into palliative care from admission, the start of the hospitalisation process. The integration of palliative care into the continuum of care, within the oncology hospitals of the provincial health sector, would need the involvement of the Professional Nurse. Harding (2012:45) found that Emergency and Oncology Nurses need palliative care standard operating procedures for the prompt identification and effective management of palliative care, and that this is necessary to ensure positive care of the cancer patient and the rendering of emotional support to families.

According to Harding (2012:45), Emergency and Oncology Nurses need to be equipped from the outset, when the cancer patient is admitted to hospital in the Emergency Department. In addition, Harding (2012:45) specified the primary tenets of palliative care (for example, symptom management) to include the establishment of goals of care in keeping with the patient's values and preferences. Secondly, these primary tenets of palliative care must be consistent, there should be sustained communication between the patient, and all those involved in his/her care. The psychosocial, spiritual and practical support should extend to the cancer patients and their family caregivers; across all sites, there should be coordinated care. The researcher hopes to show that South Africa probably has one of the most advanced palliative care systems on the continent. One of the challenges faced in palliative care is to enable people to stay at home, be cared for at home and enable their families to provide quality care.

The importance of this study is the participation of family members in providing ongoing quality palliative care to the patient after they have been discharged. The significance of this is that the patient feels supported from the time of their admission at emergency, to the ward, and from there to the Out-Patients Department (OPD), including discharge and home care. Against this background, the study aims to develop applied palliative care protocols for Emergency and Oncology Nurses, to provide best practice palliative care nursing for Oncology Patients who may present at any of the three selected Western Cape Provincial Hospitals.

1.3 Aim of the Study

The overall aim of the research was to develop applied palliative care protocols for Emergency and Oncology Nurses to provide best practice palliative care nursing for Oncology Patients who may present at any of the three selected Western Cape Provincial Hospitals. The study was conducted in three parts and had the following objectives and research questions set to achieve the goal of the study.

1.4 Research Objectives

- Objective 1 of the study was to:

- Investigate the knowledge, attitudes and practices (KAP) of Emergency and Oncology Nurses regarding palliative care nursing practices and procedures for Oncology Patients in three Western Cape Provincial Hospitals.

- Explore the experiences of Oncology Patients and their families regarding delivery of current palliative care nursing practice in three Western Cape Provincial Hospitals.

- Develop protocols for the Emergency and Oncology Nurses to ensure high quality care for Oncology Patients in three selected Western Cape Provincial Hospitals.

1.5 Research Questions

According to Strauss & Corbin (1990:39), a research question provides direction and helps the researcher to stay focused throughout the research project. It points to the interaction to be investigated, the site, the people involved and the potential participants.

❖ The following research questions directed Part 1 of this research study:

- What is the level of knowledge of the Emergency and Oncology Nurses regarding nursing care practice in palliative care for Oncology Patients with cancer in three selected Western Cape Provincial Hospitals?

- What are the attitudes of the Emergency and Oncology Nurses regarding working with patients with cancer in three selected Western Cape Provincial Hospitals?

- What palliative care nursing care practices and protocols are used for Oncology Patients in the three selected Western Cape Provincial Hospitals?

1.5.1 Phase 1

1.6 Clarification of Concepts A Quantitative Survey Using Questionnaires to Investigate the Palliative Care Knowledge, Attitudes and Practices (KAP) for the Professional Emergency and the Oncology Nurse

1.5.2 Phase 2: Part 1

Two Qualitative Studies: (A) Semi-Structured In-Depth Interviews with Oncology Patients and (B) Focus Group Discussions with Family Members of the Oncology Patients.

❖ The following research questions directed Part 2 of the study.

- What are the experiences of Oncology Patients regarding delivery of current palliative care practices in Western Cape Provincial Hospitals?

- What are the experiences of the Oncology Patients' families regarding delivery of the current palliative care practices in Western Cape Provincial Hospitals?

1.5.3 Phase 2: Part 2

The Development of Palliative Care Protocols Using the Nominal Group Technique.

- This technique will integrate data collected in Parts 1, 2 and 3, and information from the literature review.

- In addition, information will be gathered from Emergency and Oncology Nurses working in Emergency and Oncology Departments.

- Information will include that gleaned from Oncology Patients and their families in the three selected Western Cape Provincial Hospitals.

The following concepts have been operationalised for the purpose of this study (Table 1.1).

1.7 Scope of the Study

The scope of the study considers the following issues:

1.7.1 The Knowledge, Attitudes and Practices of Emergency and Oncology Nurses Regarding Palliative Care Nursing Practices/Procedures for Oncology Patients in Three Western Cape Provincial Hospitals

Cancer is a significant cause of morbidity and mortality worldwide (World Health Organisation, 2009). The knowledge, attitudes and practices (KAP) of the Professional Emergency Nurse caring for the patient diagnosed with cancer will be challenged (Kendall, 2007). Emergency Professional Nurses are the front or first reception of nursing at most government hospitals and they will be challenged to meet the needs of the patient, including those of their families, through all the stages of the cancer trajectory. This will require specialist and theoretical practical knowledge, especially if the family member readmits the patient. The family's physical and psychosocial needs are generally not being met in non-specialist oncology settings.

Table 1.1: Clarification of concepts and their operationalisation for the purpose of this study

Concept	**Operational Definition**
Death Anxiety	Death anxiety is defined as an unpleasant state of inner turmoil or dread over something unlikely to happen, such as the feeling of imminent death. Death anxiety as measured by the tool used by Frommelt (1991).
Emergency Unit	Is a medical treatment facility specialising in the acute care of patients who present without prior appointment, either by their own means or by ambulance. The Emergency Department is usually found in a hospital.
Family Member	Is operationally defined as a person who is directly involved in the care or support of the patient.
Oncology Environment	For the purpose of this study, oncology environment is operationally defined as creating a healing environment for cancer patients and their families.
Oncology Experience	This refers to the content of core knowledge and the management of Oncology Patients that requires training and experience.
Palliative Care	Palliative care is derived from the Latin *palliare*, which means "to cloak". Any form of medical care or treatment that is concentrated on reducing or relieving the suffering of patients is known as palliative care. This involves pain control and symptom management, which are the key factors, but palliative care also, deals with the social, spiritual, and emotional aspects of the patient's care (World Health Organisation, 2004).
Professional Nurse	A person who is educated and competent to practise comprehensive nursing, assumes responsibility and accountability for independent decision-making in such practice, and is registered and licensed as a Professional Nurse under the Nursing Act (South African Nursing Council, 2016).
Protocol	For the purpose of this study, protocol is a system of rules that explains the correct conduct and protocols to be followed by Emergency and Oncology Nurses working in a government hospital.

Oncology Nurses play a vital role in the provision of a safe and supportive environment to the patient and the family (Haisfield-Wolfe; 2005:97). In a survey conducted by Harding (2012), findings revealed that Professional Nurses regarded palliative care as purely communication needs. Interestingly, the findings in this study showed that the Oncology Nurse feels ill-equipped or inept to deal with feelings of discomfort, in communicating verbally and non-verbally with the Oncology Patient. Nurses involved in the study (Harding, 2012:45) indicated this.

1.7.2 The Experiences of the Oncology Patients and Their Families Regarding Delivery of Current Palliative Care Nursing Practices in Three Western Cape Provincial Hospitals

The research showed that Oncology Patients and their families in the three selected Western Cape Provincial Hospitals had different perceptions about current palliative nursing practices. The Oncology Patients' experiences of palliative care practice regarding communication and more timely, complete and accurate information on palliative care services was that this was lacking in order for them as patients to effectively participate in care and decision-making.

The experiences of the family members, of current palliative care, point to a need for a culture of caring in the holistic delivery of nursing care. The researcher noted that the psychosocial, spiritual, and practical support should extend to the cancer patients and their family caregivers across all sites in order to constitute coordinated care. The findings of the Vahid et al. (2010:9) revealed that Oncology Nurses should be aware of the need during their interactions with Oncology Patients to validate the effect of their care.

1.7.3 The Development of Protocols for Emergency and Oncology Nurses to Ensure High Quality Care for Oncology Patients In Three Selected Western Cape Provincial Hospitals

Palliative care within South Africa has undergone radical changes in the last twenty-five years (Defilippi, 2006). Literature shows that palliative care protocols do affect directly on Oncology Patients with life-limiting illnesses, and that they often experience significant suffering early in the course of the disease (Costello, 2006:94-601). The identified researched palliative protocol is a multi-dimensional conceptualisation of patient-centred care that shows how clinical, structural and interpersonal attributes can collectively influence the patient. It is essential to sustain the provision of palliative care as outlined in the WHO definition-and this includes pain and symptom management as well as providing emotional support. All these aspects must remain primary to the focus of an outcomes based Palliative Care Protocol for Emergency and Oncology Nurses in South Africa.

The central theme of this protocol focuses on the experience of the patient from his/her perspective, minimising vulnerability and maximising control and respect. The development of the concept of patient-centred care emerged from the limitations of the conventional “biomedical model” where illnesses are considered to indicate the existence of the disease (Mead & Bower, 2000). According to Edwards & Davies (2002), Professional Nurses ought to embrace the foundation of patient-centred care, because Oncology Patients are leaders and experts for their own lives, having goals that coordinate care of the patient who is consistent, and where timeliness and universal access to care are considerations.

The main advantage of the Patient-Centred Care (PCC) model is that the patient is at the centre concerning the delivery of care; and ensures re-direction of the activities in order that the right person performs the correct job at the right time. The Patient Centred Framework is about a collaborative and respectful relationship or partnership between the service provider and the recipient of the care. It is in essence a multi-dimensional conceptualisation of patient-centred care within which clinical, structural and interpersonal attributes can culminate in influencing the Oncology Patient’s experience.

1.8 Significance of the Study

This information will be used to develop palliative care protocol that may make significant contributions, namely:

- This study is unique because palliative care has been researched internationally.
- To affect the hospital culture that has not yet embraced a palliative care philosophy or protocols for Oncology Patients with terminal conditions.
- Emergency and Oncology Nurses could adopt the palliative care protocols and this could work towards improving best patient practice.

- The findings of this study could influence policy and curriculum development in training and nursing practice.

- To develop the level of knowledge of Emergency and Oncology Nurses regarding nursing care practice, in palliative care for Oncology Patients.

- To enhance the skills in improving of the attitudes of Emergency and Oncology Nurses regarding working with cancer patients

- To develop high quality palliative care nursing care practices and protocols for the Oncology Patient.

- To actively improve the experiences of Oncology Patients, regarding the delivery of current palliative care practices in the Western Cape Provincial Hospitals.

- To provide support to the Oncology Patients' families, regarding delivery of the current palliative care practices in Western Cape Provincial Hospitals.

1.9 Outline of the Thesis

The structure of the thesis is in chapter sequence as indicated in Table 1.2.

Table 1.2: Outline of the thesis by chapter

Chapter 1	Provides an orientation and background for the research. It also highlights the problem statement, aims, and objectives research questions, three parts of the research, the scope and significance of the research.
Chapter 2	Provides an overview of the literature and background to the palliative care protocol, knowledge, attitudes and practices (KAP) of the Oncology Nurse.
Chapter 3	Encompasses the literature review and the theoretical framework that forms the basis of the research.
Chapter 4	Offers a detailed presentation of the methodology used in this study.
Chapter 5	Presents an analysis and interpretation of the research findings.
Chapter 6	Expounds the findings of Part 2 and the central and emerging themes.
Chapter 7	Outlines the findings of Part 3 in relation to the development of the palliative care model.
Chapter 8	Encompasses the development of the palliative care model

1.10 Summary

Chapter 1 delineated the background of and rationale for the study. This included the aims and objectives, research questions. The three parts of the study were briefly outlined in terms of the research, outline of the scope and the significance of the research. Key concepts related to the research, as well as other concepts, including ethical concepts, used in the research were defined. The research design and methodology were briefly introduced.

CHAPTER 2

OVERVIEW OF THE LITERATURE

2.1 Introduction

The aim of this study was to develop applied palliative care protocols for the Professional Emergency and Oncology Nurse to provide best practice palliative care nursing for Oncology Patients who may present at any one of the three-targeted Western Cape Provincial Hospitals. The following objectives were identified: to investigate the knowledge, attitudes and practices of Emergency and Oncology Nurses regarding palliative care nursing practices and procedures for Oncology Patients in three Western Cape Provincial Hospitals to explore the experiences of Oncology Patients and their families regarding delivery of current palliative care nursing practice in three Western Cape Provincial Hospitals. To this end, Chapter 2 provides an overview of the literature related to the concept, as well as study definitions and theoretical underpinnings relevant to the study. In addition, a detailed literature review is provided as part of the discussion of the findings presented in Chapters 5 and 6.

2.2 Literature Sources

Various strategies were adopted to review the literature. Firstly, the major bibliographic databases were searched: Google Scholar, Science Direct and EBSCO Host. The University of the Western Cape, Bellville, South Africa, which included, but were not limited to, the Cumulative Index of Nursing and Allied Health (GNAHL), provided databases. Medline sources included the World Health Organisation (WHO), Palliative Health Library, Centre for Disease Control and Prevention, Morbidity and the Mortality Weekly Report (CDC-MMWR). The CINAHL (Cumulative Index to Nursing and Allied Health Literature), British Journal of Oncology, BMJ Clinical Evidence, Oncology Nursing Info, PubMed, the Canadian Journal of Oncology Nursing, Cochrane Review

Journals and the America Journal of Oncology were also used. A hand manual search was used in the articles that provided relevant information for further sources, for example, books, journals, and legislation or policy statements.

2.3 Background to the Palliative-Care Protocol

Palliative care was formally defined in 1989 and the definition later published by the World Health Organisation (WHO, 2002), as "…an approach that improves the quality of life of patients and their families encountering problems associated with life threatening illness, through the prevention and the relief of suffering by means early identification, and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

During the 1950s, new studies undertaken by doctors, social workers and social scientists had provided insights into the clinical and social aspects of terminally ill patients. These clinical and social studies formed the foundation of the Margaret Bailey Survey that was based on terminally ill patients who had been diagnosed with lung cancer. This survey was conducted at the Brompton Hospital and the Royal Marsden Hospital; both hospitals were situated in London. The content of the survey was research into the public opinion of cancer care for patients with terminal illness. A summary of the findings of the survey by Harding (2005:1971) accentuated the fact of a palliative care protocol not being understood and the fact that hospitals appear to be trying to cure all their patients, and failing in a high proportion of the cases.

The pioneering work of Cicely Saunders in palliative care findings contributed towards palliative care in the management of patients in the terminal stages of cancer. However, forty years later, Mike Richards, known then, as the "cancer tsar" was a professor in Palliative Medicine engaged in research that had expanded on the work of the Expert Advisory Group on Cancer by providing a policy framework, which would serve as the commissioning of cancer services submitted to the Chief Medical Offices of England and Wales (Saunders, 1960:403-407).

By the mid-1960s, research was conducted by Eric Walters (who founded St. Luke's Hospice in the UK). He stated that there was no valid reason why palliative care protocols and palliative care were so inadequate. In 1971, the United States of America's then President Richard Nixon declared "a war on cancer". The so-called "battle" consisted of the identification of palliative care protocols that needed urgent attention, for the early identification and the prompt execution of developing effective measures to treat those who had malignancies (Grob, 2002). In so doing, the development and execution of effective measures had introduced the softer side to this approach than had President Nixon had declared, "War on Cancer". The result was the emergence of new ideas and approaches, which formed the foundation for Modern Oncological Palliative Care.

Sociological interest in the approach was sparked in the 1970s in the United States of America (USA); this is illustrated by the contributions of Glaser and Strauss in their ethnographic studies of the care of dying patients (Clark, 2007:431). These studies were conducted in USA hospitals. A large survey conducted by Cartwright (1973), was based on 960 bereaved relatives and they were asked about the experiences they had encountered within the year of the passing of the Deceased. The findings of this survey by Cartwright (1973) contributed to the body of knowledge on curative and palliative measures and later became instrumental in defining a new protocol and a new knowledge based on the care of terminally ill patients who were dying from malignancies. The conclusion of his research was simple, as quoted by Cartwright (1973), "…constant pain needs constant control." The findings further recommended that analgesics be administered as a process method of regular pain medication, which would ensure that pain was preventable, providing the analgesic is provided in advance.

The first hospice in Japan served as a Christian base established in the Yodogwa Christian Hospital in 1973, and by the end of the century, the country had 80 In-Patient units (Marugama, 1999). In Australia, the contribution to palliative care protocol was the introductory WHO steps of the three-step analgesia ladder. This study was implemented in China in 1991 (as a result of the WHO steps of the three-step analgesia ladder) and 2002 hundreds of palliative care established services established in urban areas. The Gold Standards Framework is based on the End-of-life (EOL) approach, that is, when the terminally ill patients' needs are identified and their EOL care needs are then assessed, and then from the assessment a plan is formulated. The plan involves the relevant agencies, who are part of the staff support system. One of the primary functions of the Gold Standards Framework is to manage the symptoms of pain control for the terminally ill patient based on an assessment. The team workers identified as the relevant agencies and the Professional Nurse working within the hospice structure do this assessment.

The vision of the North West End-of-life Care Protocol is categorised into key goals. An important one is that members work as a health care team, and have the frontline staff needed to take decisions about services. The Health and Social Care staff should be able to refer the terminally ill patient to the best service regardless of organisational boundaries. For the Professional Nurse this protocol has continuing training and ongoing professional development. Quality Management is upheld with the North West Universities to ensure that courses offered are fit for purpose.

The goals of the international programme in Liverpool are to create an excellent EOL care for people living within the North West, and to encourage the use of EOL tools, for example, symptom control and psychological support. Health care workers such as the Professional Nurse receive guidance on how to render the best practice for the care of the dying; this includes the provision of comfort measures. Palliative care protocols have traditionally been imported from the United Kingdom or other countries abroad. Palliative care in South Africa has undergone radical changes within the last twenty-five years (Defilippi, 2006). The realisation of the need for greater collaboration and networking was a by-product of the medical profession's attempts to address the Human Immunodefiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) epidemic, to support those living with HIV/AIDS. The researcher has noted that there is currently very scanty literature pertaining to the importance of an educational palliative protocol in South Africa (Harding, 2005:1971).

The recently validated African Palliative Care Association (APCA) will provide excellent opportunities for published research. Even with these opportunities, there is a wide range of palliative care standards and these standards need to be assessed against uniform standards of care, an example of which would be a protocol for palliative care in South Africa. The International Society for Quality in Health Care (ISQua) has stated that to improve the quality of these standards is an ongoing process. The researcher acknowledges the statement of ISQua, and will survey the process in the development of guidelines that endeavour to facilitate quality care.

As further stated at the Palliative Care Trainers Declaration in 2002, the provision of palliative care requires policy and education that focus on the patients and their families as elements on the continuum of health care in South Africa. The main thrust of the Palliative Care Trainers Declaration was to provide research into an ethical training protocol of palliative care in order to establish training programmes for all levels of training. According to the Journal of Palliative Medicine (2003:339), this training is vital. It is essential to sustain the provision of home-based palliative care as outlined in the WHO definition, which includes pain and symptom management, and the provision of emotional support. All these aspects must remain primary to the focus of an outcomes based Palliative Care Protocol for professional nursing in South Africa.

- Barriers Related to the Palliative Care Protocol

The barriers related to the Palliative Care Protocol for professional nursing internationally are discussed in a study by Mazanec et al. (2009:11), known as the New Protocol of Palliative Care for Oncology Patients with advanced disease. A major obstacle, according to the findings of the Mazanec study, was the burden of supporting the family member financially at the EOL. Many families were already burdened with financial difficulties related to, for example, loss of work, the cost of therapy, and the other expenses associated with cancer care. Based on a comparison between hospital care and hospice care, an additional obstacle, said researchers, was that the bereavement support in hospitals was not as comprehensive as that of hospice. A major potential barrier to the use of this foreign protocol by Mazanec et al. (2009:11) was the use of the protocol for access. For the protocol to be successful, it must be available for patients, and this includes their families. Most importantly, the availability may be affected by the decisions of Professional Nurses who do not access palliative care services for their patients. This is a very important principle for this researcher, i.e., that the protocol must be available. Further to this, the misconception that palliative care should be offered only when treatment options have been exhausted or the patient is on the verge of dying, is a major obstacle that hinders the access for the delivery of EOL care. The barriers to the Palliative Care Protocol are related to the limitations governing the development of a protocol for palliative care for the professional emergency nurse and the Oncology Nurse. The protocol for the current provision of palliative care in South Africa is based on the Integrated Home-Based Care Approach Protocol.

However, the obstacle facing the Palliative Care Protocol is that this is an integrated protocol that concentrates on the advocacy of Anti-Retroviral Treatment (ART) and is designed specifically for people living with HIV/AIDS; it does not apply to any other condition. The Integrated, Home Based Care Approach Protocol does not address the issue of prompt delivery of high quality palliative care. The input and buy-in of the General Registered Professional Nurse is necessary in order to establish training programmes. Control of pain and symptoms is a human right and this includes prevention and relief of suffering by means of early identification, and the effective assessment of pain (Van Den Berg et al., 2006-287).

The World Health Organisation (2002) defined palliative care as an approach that improves QOL for patients and their families facing the problems associated with life-threatening illness, through the prevention and the relief of suffering by means of early identification and impeccable assessment, and the treatment of pain and other problems. This involves physical, psychological and spiritual care. Palliative care means a shift in the approach from curative modalities to comfort-focussed care, which aims to improve the person's quality of daily life by providing relief of symptoms through psychological and supportive care, alongside medical treatment (Van Niekerk & Raubenheimer, 2014:138).

Palliative care differs substantially from hospice care in that hospice care focuses on the end stages when the patient is terminal with advanced cancer, whereas palliative care commences from the onset of diagnosis to disease progression and finally to EOL care, including family bereavement. Palliative care is provided through comprehensive management of the physical, psychological, social and spiritual needs of Oncology Patients while remaining sensitive to their personal, cultural, and religious values and beliefs.

Internationally, the science of palliative care has undergone rapid developments, most notably with advances in the pharmacological interventions to relieve chronic pain. Currently, palliative care in Africa is witnessing increasing and concerted efforts to improve the quality of EOL care. The current statistics of the Cancer Association reveal an increase in newly diagnosed cancer cases and is one of the leading causes of deaths in South Africa. Since the modern hospice movement began during the 1950s into the 1960s, it has been estimated that hospice and palliative care services have been established in over 120 countries throughout the world (Wright & Clark, 2006:7).

The World Health Organisation (WHO) estimates that approximately 9.67 million people are in need of palliative care across Africa (Van Niekerk & Raubenheimer, 2014:138). A multi-centre study conducted in Africa has established that the proportion of people requiring palliative care could be at least 0.5to 1% of the population. The need for palliative care among hospital In-Patients has been well documented in Europe, but is not well established in Africa and South Africa in particular (Van Niekerk & Raubenheimer, 2014:38).

In South Africa, the situation regarding palliative care is that approximately 80% of Oncology Patients are presenting with advanced incurable progressive disease (Freund, Battaglia, Calhoun, Dudley, Fiscella, Paskett & Roetzheim, 2008:3391-3399). In South Africa, there are more than 60 organisations that are linked to the Hospice and Palliative Care Association of South Africa (HPCA); these provide a range of services for patients and their families. Cancer, according to Maree (2007:887), has an intense effect on the physical and the psychological dimensions of the sufferer. A study was undertaken to investigate the preferences for outcomes and risks involved in treatment (Varga & Paulus, 2015:443-449). The emphasis of the research was to highlight the fact that the palliative patient has holistic needs, and to examine the role of the family in improving the QOL of the patient. The study also looked at pain relief, addressing and reducing the suffering of the patient (Varga & Paulus, 2014:443-449).

The application of palliative care protocols is not an alternative to other care, but something that is complementary, and an essential component of holistic total patient care. The literature illustrates that palliative care protocols do affect directly on the Oncology Patients with life-limiting illness, and that they often experience significant suffering early in the course of the disease (Costello, 2006:94-601). Many Emergency and Oncology Nurses need palliative care protocols that would enable them to manage the patient and the family within the organisation, with insight into palliative care from the start of the admission process (Feldstein & Gemma 1995:85-236).

The integration of palliative care into the continuum of care, within the oncology hospitals of the provincial health sector necessitates the involvement of the Professional Nurse (Harding, 2012:45). Emergency and Oncology Nurses need to be prepared from the start of the Oncology Patient's admission to hospital in the Emergency Department (Feldstein & Gemma, 1995:85-236).

2.4 Knowledge, Attitudes and Practices of the Oncology Nurse

Research shows different perceptions of Oncology Nurses working in Oncology Departments, and of their attitudes and practices and how they come into play in cancer patient care. The essence of nursing is caring. Caring, needs to be based on mutual understanding between Professional Nurse and patients (Vahid et al., 2010:9). Particularly the Oncology Patient and the Oncology Nurse interact with and perceive each other in the context of highly physical forms of care. The findings of Vahid et al. (2010:9) revealed Professional Nurses ought to be mindful of these considerations during their interactions with Oncology Patients, as well as the effect of their caring in relation to their intentions towards their patients. Communication is vital for the emotional and communication issues with patients and their families. Kubler-Ross (1969:269) underscored the importance of effective communication and highlights the importance of effective direction in verbal and non-verbal communication between the Professional Nurse and the patient, in maintaining a positive relationship.

Furthermore, Kubler-Ross (1969:269) emphasised that the Oncology Nurse needs support and protocol because of his/her involvement in both life and death issues, as well as the demands of caring for certain Oncology Patients over indefinite periods of time. To further substantiate this notion, a study undertaken by Costello (2001) with Oncology Nurses identified communication skills as a problem area. Costello argued that there was a lack of effective and open honest communication about future planning or bereavement requests of the patients.

Another study demonstrated that Professional General Registered Nurses working in an In-Patient Oncology Unit were found to be stressed out and anxious about the emotional aspects of openly sharing, or about what to share and what not to share (Buys & McDaniel, 1996:103). Professional General Registered Nurses in this study indicated that they had difficulties in adjusting to work in the Oncology Departments of cancer hospitals or hospices, and caring for Oncology Patients in an environment in which death is a daily reality. The literature indicates that nursing as a professional discipline places the greatest demands specific to the development and refinement of the caring concept (Zamanzadeh, Azimzadh, Rahmani & Valizadeh, 2010:10).

The Oncology Nurse plays a vital role in the provision of a safe and supportive environment for patients and their families (Haisfield-Wolfe, 2005:97). A survey conducted by Kirby et al. (2014), revealed in its findings that the Professional Nurse regarded palliative care purely as communication needs. Interestingly, the findings showed that this perception made the Oncology Nurses feel ill equipped and unable to deal with feelings of discomfort, in communicating verbally and non-verbally with the Oncology Patient (Kirby et al. 2014:1136).

The role of the Oncology Nurse, according to Kirby et al. (2014:1136), is most germane when nursing staff have to engage with terminal patients regarding their diagnoses. This is often the patient’s most vulnerable time, where s/he experiences feelings of futility. Referral of the palliative care patient in such situations has been virtually ignored in the clinical literature. Specifically, Professional Oncology Nursing plays a vital and sensitive role in facilitating patient transitions to palliative care. The lack of attention paid to the transition of the patient is often experienced by the Professional Nurse as an emotional burden. It is hard to balance the interpersonal and the inter-professional relationship during this time that, in turn, leaves them feeling professionally unsupported (Kirby et al., 2014:1136).

CHAPTER 3

THEORETICAL FRAMEWORK

3.1 Introduction

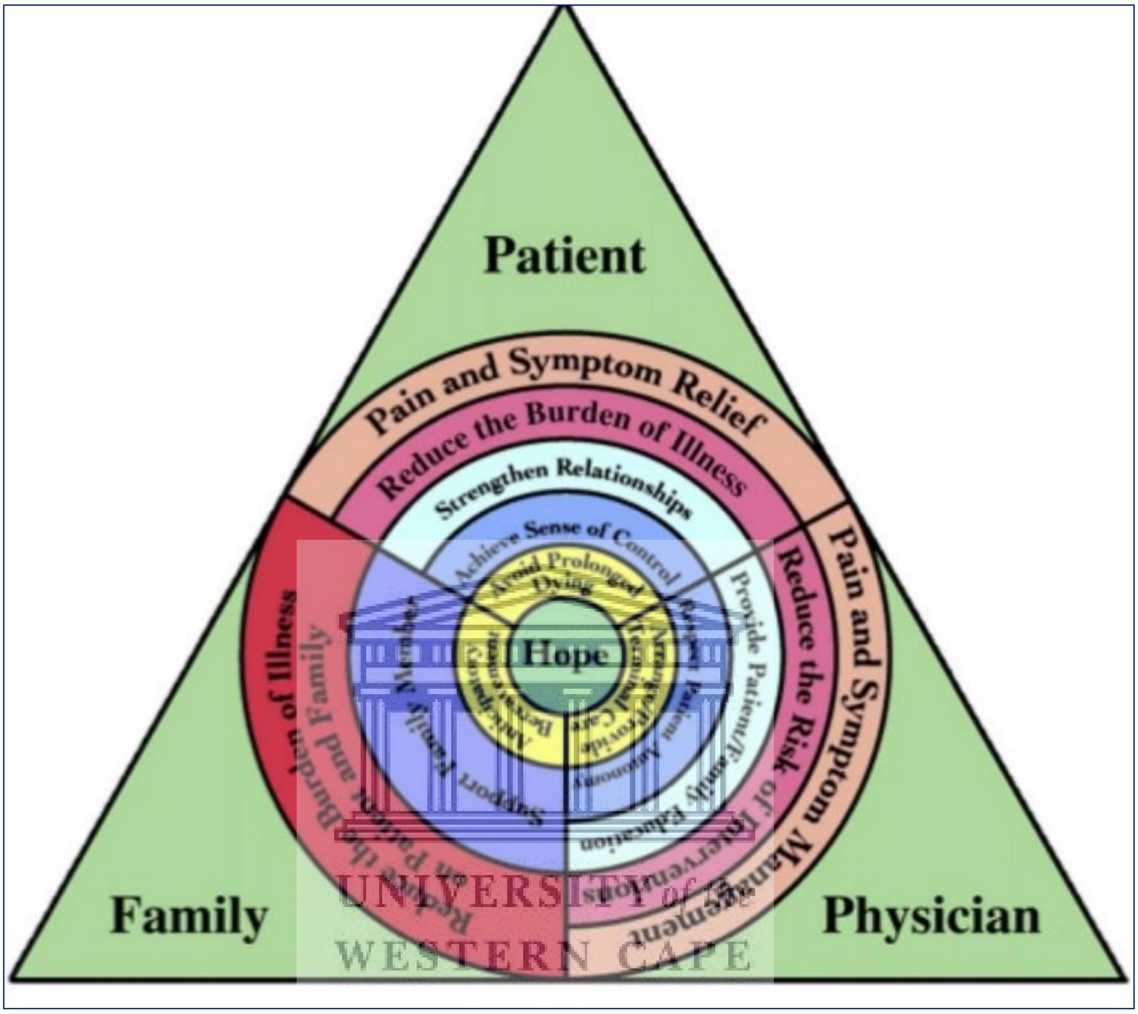
This chapter provides the theoretical framework of the study. The objective of the study was to investigate the knowledge, attitudes and practices of Emergency and Oncology Nurses regarding palliative care nursing practices and procedures for Oncology Patients in three Western Cape Provincial Hospitals. Secondly, to explore the experiences of Oncology Patients and their families regarding delivery of current palliative care nursing practice in three Western Cape Provincial Hospitals. The theoretical framework for this study was to use theory that coordinates the richness of meaning in qualitative enquiry (Van Rensburg and Smit, 2004:25). The Palliative Pyramid supported by the Patient-Centred Care model underpinned this study.

3.2 The Palliative Care Pyramid

The palliative care pyramid is a palliative care focused framework that includes the patient, the family and the health professionals, as developed by Makowzki (2012). It includes a focus on pain and symptom management, reducing the burden of illness, strengthening relationships, ensuring patient information, respect and patient autonomy, allowing a sense of control, supporting the family, and avoiding prolonged dying.

3.3 The Patient-Centred Care Model (PCC)

The Patient-Centred Care (PCC) model was chosen because of the focus of the Palliative Care Pyramid on the involvement of Oncology Patients and their families in this study. PCC does involve the patient in all forms and aspects of care. PCC is a direct change of mind-set from medical practice, which gave minimal attention to communication (Shaller, 2007). This model is a multi-dimensional conceptualisation of PCC that shows how clinical, structural, and interpersonal attributes can collectively influence the patient. The central theme of this model focuses on the experience of the patients from their own perspectives, minimizing vulnerability and maximizing control and respect. The development of the concept of PCC emerged from the limitations of the conventional "biomedical model" where illnesses are considered to indicate the existence of the disease (Mead & Bower, 2000).



Source: Makowski, S. (2012) *Health & Medicine*: https://www.slideshare.net/suzanakm/surgical-grand-rounds-palliative-care; https://www.slideshare.net/featured/category/health-medicine; Accessed 9 February 2018.

Figure 3.1: The palliative care pyramid

According to Edwards & Davies (2002), Professional Nurses should embrace the principle and practice of PCC, because Oncology Patients are advocates for and experts in their own lives. Patient-centred care sets goals that coordinate care of the patient who is consistent, timeliness and universal access to care. The main advantage of the PCC is the patient at the centre concerning the delivery of care and re-directs the activities to ensure that the right person performs the correct job at the right time.

3.4 Application of the Framework in the Study

The overall pyramid was used to underpin an investigation into nurses' knowledge, attitudes and practices in palliative care in addressing the following questions:

- What is the level of knowledge of Emergency and Oncology Nurses regarding nursing care practice, in palliative care for Oncology Patients with cancer in three selected Western Cape Provincial Hospitals?

- What are the attitudes of Emergency and Oncology Nurses regarding working with patients with cancer in three selected Western Cape Provincial Hospitals?

- What palliative care nursing care practices and protocols are used for Oncology Patients in the three selected Western Cape Provincial Hospitals?

The PCC will provide a context for the exploration of the palliative care experiences of patients and their families in addressing the following questions:

- What are the experiences of Oncology Patients, regarding delivery of current palliative care practices in Western Cape Provincial Hospitals?

- What are the experiences of the Oncology Patients' families, regarding delivery of the current palliative care practices in Western Cape Provincial Hospitals?

The Patient-Centred Care model to address the abovementioned questions underpinned this study. In addition, the Patient-Centred Care Protocol (PCCP) was chosen because it is applicable to research into the active involvement of Oncology Patients (and this includes their families) from the time of admission, in decision-making about individual options for treatment. PCCP involves the patient and the family in all forms and aspects of care and is a significant change of mind-set and orientation from conventional medical practice and its communication (Shaller, 2007).

3.5 Background of the Patient-Centred Care Protocol

This protocol is a multi-dimensional conceptualisation of PCC that shows how clinical, structural, and interpersonal attributes can collectively influence the patient and the family. The central theme of this protocol focuses on the experience of the patient from his/her perspective, minimizing vulnerability and maximizing control and respect. The Patient-Centred Framework is about a collaborative and respectful relationship or partnership between the service provider and the recipient of care. In essence, a multi-dimensional conceptualisation of PCC shows how clinical, structural and interpersonal attributes can all work together to influence and affect the Oncology Patient's experience:

- Information Sharing

This includes the ability of the health care practitioners to communicate and share complete and unbiased health information with Oncology Patients in ways that are affirming and useful. Oncology Patients should receive timely, complete and accurate information on palliative care services in order to effectively participate in care and decision-making.

- Participation

Oncology Patients are encouraged and supported in participating in care and decision-making at the level they choose. This ensures proper identification of barriers and challenges of palliative care as well as shared decision-making based on best available evidence, which is also informed by the patient's preferences.

3.6 Application of the Patient-Centred Care Protocol

In adopting the concept of Patient-Centred Care Protocol, the principles of the protocol were applied as follows:

- The overall pyramid was used to underpin an investigation into nurses' knowledge, attitudes and practices in palliative care.

- The PCC model provided a context for the exploration of the palliative care experiences of patients and their families.

- The PCC model underpinned this study.

- The PCCP was chosen because it is applicable to the research into active involvement of Oncology Patients in their own treatment.

- The Oncology Patients' families, from the earliest time of admission to the hospital, were interviewed about decision-making concerning individual options for treatment.

- This included information for Emergency and Oncology Nurses regarding the focus on pain and symptom management.

- Questionnaires were distributed to Emergency and Oncology Nurses, covering such items as reducing the burden of illness, strengthening relationships, patient information, respect and patient autonomy allowing a sense of control, supporting the family, and avoiding an unnecessarily attenuated death experience.

3.7 Summary

The palliative care framework and the PCC model was discussed. The application of both frameworks in addressing the application of both frameworks, in relation to the attitudes of Emergency and Oncology Nurses regarding working with patients with cancer in three selected Western Cape Provincial Hospitals. The application of the PCC model for patients were highlighted. The experiences of Oncology Patients, from the onset of admission, regarding delivery of current palliative care practices the experiences of the Oncology Patients' families, regarding delivery of the current palliative care practices whilst their family member is in hospital. The Palliative Care Pyramid and the Patient Centred Care Model was selected to guide the investigation of the knowledge, attitudes and practices of Emergency and Oncology Nurses regarding palliative care nursing practices and procedures. The theoretical frameworks were further selected to explore the experiences of Oncology Patients and their families regarding delivery of current palliative care nursing practice. Chapter 3 will focus an overview of the literature and background to the palliative care protocol, knowledge, attitudes and practices of the Oncology Nurse.

CHAPTER 4

METHODOLOGY

4.1 Introduction

The purpose of this chapter is to describe and justify the research methodology and to generate answers to the research questions. The research design, research setting, sampling technique, research instruments, data collection techniques and cleaning of the data are described (Blanch, Durkheim & Painter, 2006). The overall aim of the research was to develop palliative care protocols for Emergency and Oncology Nurses to provide best practice palliative care nursing for Oncology Patients who may present at the Western Cape Provincial Hospitals, i.e., Groote Schuur, Tygerberg and Victoria.

The study is divided into two phases:

- **Phase 1:** A quantitative survey using questionnaires to investigate the palliative care knowledge, attitudes and practices of Emergency and Oncology Nurses.

- **Phase 2:** Included two qualitative studies, namely:

- **Phase 2: Part 1:** A focus group with family members of Oncology Patients and semi-structured in-depth interviews with Oncology Patients.

- **Phase 2: Part 2:** Deals with the development of a palliative care protocols using the Nominal Group Technique. This technique was used by integrating the data collected in Phases 1 and 2, and information from the literature review, as well as information gathered from Emergency and Oncology Nurses working in the Emergency and Oncology Departments, Oncology Patients and their families.

Research was confined to the three selected Western Cape Provincial Hospitals. In this chapter, the literature review on the research methodology is presented. The overall research design was a concurrent mixed method using a quantitative survey questionnaire for Emergency and Oncology Nurses, concurrent exploratory descriptive focus groups with the families of Oncology Patients, and semi-structured in-depth interviews with Oncology Patients in the Oncology Out-Patient Department. The research design is described, as are the research instruments, sampling criteria and techniques, data collection and data analysis. Explanatory sequential mixed method design was used to collect the data. According to Hayes, Bonner & Douglas (2013), explanatory sequential concurrent mixed method design first uses quantitative methods to collect and analyse data, which is followed by qualitative methods. The authors make the point that quantitative methods precede, and are integrated with qualitative results, occurring at the interpretation stage of the study.

Quantitative data were collected to investigate the knowledge, attitudes and practices of the Emergency and Oncology Nurses regarding palliative care nursing practices/procedures for Oncology Patients in three selected Western Cape Provincial Hospitals. The finding from Quantitative Objective 1 informs the qualitative study. The qualitative data were collected to address the exploration of the experiences of Oncology Patients and their families, regarding delivery of current palliative care nursing practices in three selected Western Cape Provincial Hospitals.

The overall research design was a concurrent mixed method using a quantitative survey questionnaire for Emergency and Oncology Nurses, concurrent exploratory descriptive focus groups with the families of Oncology Patients and semi-structured in-depth interviews with Oncology Patients in the Oncology Out-Patient Department. Concurrent mixed method research combines methods that cross two primary research approaches or paradigms in the same study. Methods include the full range of techniques or strategies used to sample participants and to gather data. It is significant that within this process there is blending or bringing together of methods within one study, and that the study uses mixed methods concurrently. To ensure that the value, robustness and integrity were maintained, attention was directed towards the integration of qualitative and quantitative data (in the nominal group process), that produced outcomes that were greater than the sum of the constituent parts. The ethical considerations relevant to the study are discussed at the end of this chapter.

4.2 The Study Approach

The underlying research paradigm is pragmatism. Pragmatism is not restricted to a single system of philosophy and reality, in that researchers apply methods of both quantitative and qualitative approaches (Burns & Grove, 2012). Firstly, positivist assumptions were used to address Objective 1. Secondly, constructivist assumptions were applied to achieve Objective 2. According to Burns & Grove (2012), positivist assumptions align themselves with philosophies of quantitative methods of inquiry that use strict rules of truth, law and logic. Constructivist philosophy asserts that reality exists as a social construct in the minds of individuals (Mills, Bonner &Francis, 2006).

This extends to the manner individuals construct their own understanding and knowledge of phenomena through experience. The researcher ensured that she did not interfere with the data collection process by allowing participants to freely respond to the items on the questionnaire. In clinical research, the researcher should use the simplest manner of collecting the data to get answers to the research question and should not collect any more data than necessary. Pragmatism underpins this study to ensure complete and holistic descriptions of the findings (Burns & Grove, 2012:375).

4.3 Research Setting

The research was conducted with participants from Oncology Wards, oncology Out-Patients Departments, and the Emergency Departments of three selected government hospitals of the **Western Cape Province**. These three government hospitals were purposively selected because they are the three hospitals that supply the most extensive oncology services in this province.

Tygerberg Hospital is a tertiary hospital located Parow Valley, Cape Town, South Africa. The hospital was officially opened in 1976, and is the largest hospital in the Western Cape and the second largest hospital in South Africa, with a capacity for 1899 beds. It acts as a teaching hospital in conjunction with Stellenbosch University‘s Health Science Faculty. To become a patient at Tygerberg, a person must be referred by a primary or secondary health care facility.

Over 3.6 million people per year receive health care from Tygerberg Hospital, either directly or via its secondary hospitals, Paarl and Worcester Hospital. The Radiation Oncology Unit has four dedicated clinics to treat a variety of cancers using state-of-the-art equipment and a dedicated Computed Tomography (CT) scanner on site for cancer planning. The unit has hosted the very first prostate brachytherapy seminar in the country and has a dedicated children’s room for pediatric oncology cases.

Groote Schuur Hospital is one of Cape Town’s premier tertiary academic hospitals and was officially opened in 1938. The hospital is internationally renowned as the training ground for some of South Africa’s best doctors, surgeons and nurses. The Department of Radiation Oncology maintains an Oncology service for cancer patients in the Western Cape. The service is organised around 23 multi-disciplinary clinics. The department provides support for patients from the George region. A Public Private Initiative was successfully introduced so that state patients in the George region could receive their treatment in George. Activities are reviewed by teleconference every 3 months.

Victoria Hospital is a Secondary Hospital situated in the southern suburbs of the Western Cape, South Africa, and is known for the high standard of care as well as its concern for the population it serves. It provides a wide range or both medical and surgical services and strives to reach out to the community that surrounds it. A hospital-based hospice/palliative care organisation specialises in Organ Failure Patients. However, due to the enormous need for palliative care, this facility cannot service all who need it.

Table 4.1 summarises the professional emergency and oncology nursing staff at the three hospitals.

Table 4.1: Emergency and oncology nursing staff at the three hospitals

Hospital	Emergency Department	Oncology	Palliative Care Staff
Groote Schuur Hospital	20	15	±35
Victoria Hospital	8	4	±12
Tygerberg Hospital	10	8	±18
Total (n)	**38**	**27**	**65**

4.4 PHASE 1: Quantitative Survey Using Questionnaires to Investigate the Palliative Care Knowledge, Attitudes and Practices for Emergency and the Oncology Nurses

4.4.1 Data Collection Instruments

A combination of data collection instruments was used (Table 4.2). These included focus group (family of the Oncology Patient) and semi-structured individual (Oncology Patient) interviews. Questionnaires were used with the Emergency and Oncology Nurses; the aim was to investigate their knowledge, experience and perceptions of palliative care. Data collection commenced in early April 2017 and was completed in July 2017. The questionnaire consisted of four sections.

They were as follows:

- Section A: Demographics
- Section B: Knowledge using the Palliative Care Quiz
- Section C: Familiarity and Practice questions based on SA Hospice Association Guidelines (Hospice Palliative Care Association of South Africa, 2014).
- Section D: Attitudes towards Nursing of the Dying using the Frommelt Attitude towards Care of the Dying Scale (FATCOD).

The Palliative Care Quiz is a nursing quiz on common palliative care nursing knowledge that was developed by Ross (1996). The quiz has 20 questions. Answer options are: True, False or Don't

Know and a total correct score is calculated. The Frommelt Attitudes toward Care of the Dying (FATCOD) is a 30-item tool using a Likert scale to indicate respondents' attitudes towards caring for patients who are dying (Lange et al., 2008: 956). The FATCOD Scale is a 30-item scale designed so that two-thirds of the statements address nurses' attitudes toward the dying patient, while the other third addresses nurses' attitudes toward the patient's family (Frommelt, 1991).

Questionnaires are often used in descriptive studies to gather information such as demographic data of the respondents, their attitudes or opinions, and knowledge of these respondents in a certain situation (Burns & Grove, 2009:239). In this study, only closed-ended questions were included, where respondents had to select an answer from a list of responses provided.

Closed-ended questions ensure standardization of responses that can be processed more easily (Babbie, 2007:246). The researcher compiled a self-reporting questionnaire, consisting of four sections. In self-reporting questionnaires, respondents are requested to complete the questionnaires themselves (Babbie, 2007:257). Section A of the questionnaire collected data for measurement on the Nominal Scale level. This refers to data being categorized according to a defined property, where each item only fits into one specific category (Burns & Grove, 2009:375).

Using this kind of measurement, the categories cannot be ordered into different ranks and the numbers used for coding the data cannot be used in calculations (Burns & Grove, 2009:375). The categories of data included in Section A are the demographic information of the respondents—age, gender, the years of experience as a Professional Nurse, if they had received recent training (in the past year), the referral pathway and years of experience in caring for Oncology Patients.

Table 4.2: Summary of the study methodology

Method		**Instruments**	**Population**	**Sampling**	**Analysis**
Phase 1	**Quantitative Survey**	• Questionnaire, which consisted of four sections. Section A: Demographics; Section B: Knowledge using the Palliative Care Quiz, Section C: Familiarity and Practice questions based on SA Hospice Association Guidelines (Hospice Palliative Care Association of South Africa, 2014) • Familiarity and Practice questions based on SA Hospice Association Guidelines, Hospice Palliative Care Association of South Africa (2014) • Section D Attitudes towards nursing of the dying using the Frommelt Attitude towards Care Of the Dying Scale (FATCOD). • The Palliative Care Quiz is a nursing quiz on common palliative care nursing knowledge that was developed by Ross (1996).	**Emergency and Oncology Nurses**	**Purposive**	**Descriptive statistics (SPSS 24)**
Phase 2: Part 1	**In-Depth Interviews**	Semi-structured questions-**prompted the discussion**	**Oncology Patient**	**Purposive**	**Atlas.ti**
Phase 2: Part 2	**Qualitative Focus Group Discussions**	Objectives of the study guided the discussion	**Family of the Oncology Patient**	**Purposive**	**Atlas.ti**

In sections B, C and D, the variables were measured on an Ordinal Scale level. The variables were ranked into exclusive and exhaustive categories, with the intervals between the ranked categories unequal (Burns & Grove, 2009:375). A Likert-Type Scale was used to measure the attitudes and opinions as a Professional Nurse. Likert scales are used to determine the opinions or attitudes of a respondent and they include declarative values of each statement. The values can range from, for example, strongly agree to strongly disagree (Burns & Grove, 2009:410). In section B of the questionnaire, an existing scale, namely the Frommelt Attitude Towards Care of the Dying (FATCOD) scale was applied to measure the Oncology Nurses' attitudes towards caring for the dying patient. The FATCOD scale is a thirty-item Likert scale instrument, having five possible response categories, ranging from strongly disagree to strongly agree (Lange et al., 2008:956). Two thirds of the items referred directly to the respondents' attitudes towards the dying patient, whilst one third referred directly to the attitudes towards the family of the patient (Mallory, 2001:38).

The scale further consisted of an equal number of positively and negatively worded statements. Scoring was reversed for the negative statements. The researcher changed the original five response categories to six, by replacing the "uncertain" category with two other categories, namely, "slightly disagree" and "slightly agree". The motivation for this adjustment was to prevent respondents from selecting the neutral, uncertain category and to pressure them to agree or disagree with a statement. The scores of the FATCOD scale ranged between 30-180, with the higher scores representing more positive attitudes towards 38, i.e., as caring for patients who are dying.

In section C, a seven-item Likert scale questionnaire, as developed by Biton & Tabak (2002:147), to measure knowledge and experience of palliative care, was used. The Likert scale in this instrument included eight response categories, ranging from familiar to not familiar, used always or not always used. An eight-item Likert scale with six response categories, ranging from never to always, was compiled from an analysis of previous studies by Traynor & Wade (1993:131).

4.4.2 Reliability and Validity in Quantitative Research

In quantitative research, reliability is concerned with how consistently the measurement technique measures a variable or concept. In addition, it specifies the extent of random error in the method of measurement (Burns & Grove, 2009:377). Random error is a measurement error that refers to the difference between the measured value and the true value of a measurement (Burns & Grove, 2009:372). According to Delport (2005:163), a data collection instrument is reliable if it produces identical or nearly identical measurements, and if the same variables are measured under the same conditions. Since the FATCOD scale was employed in various previous research studies to assess the attitudes of nurses towards caring for dying patients, the reliability of this instrument had been confirmed unequivocally. Lange et al. (2008:956) used a test-retest procedure to assess the reliability of the original FATCOD scale.

4.4.3 Validity of the Data Collection Instrument

The validity of the items regarding the knowledge and experience of the Professional Emergency and Oncology Nurse was established during the pilot study. According to Burns & Grove (2003), the number of research workers involved can have a negative influence on the reliability of a study. Therefore, in order to minimise unreliability from using several research workers, the researcher ensured that she was solely responsible for distributing and collecting the questionnaires. Validity in quantitative research is the extent to which the instrument actually reflects or measures what it is supposed to measure (Burns & Grove 2009:380). **Content validity** is concerned with the content of the instrument and whether they cover the full range of meanings of the variable(s) being measured (Delport, 2005:161). The instruments in this study were used to measure nurses' attitudes towards caring for patients who are dying.

The Palliative Care Quiz appears to have good validity though no detailed psychometrics were extracted from the exercise (See Osman et al., 1994 for details on The Pain Anxiety Symptoms Scale: psychometric properties in a community sample). The FATCOD has well established validity and reliability with an agreement of 1.0 (Frommelt, 1991). In addition, face and content validity of the overall tool should be considered. **Face validity** checks that the questionnaire actually measures the concept being tested. This will be assessed by asking palliative care specialists to review the questionnaire to see if the questions appear relevant, clear and unambiguous, as outlined by Jack et al. (2013:2778-2786). Content validity is established by measuring knowledge using the Palliative Care Quiz, which addressed Pain and Symptom Management. Attitudes were measured using the FATCOD scale, and practices by using the core guidelines for clinical, psychosocial, information sharing, patient and family respect and autonomy.

4.4.4 Reliability of the Instrument

Reliability in quantitative research of the data collection tool refers to the measurement technique, the accuracy of measurement, the stability and consistency (Polit & Hungler, 2010). Cronbach's Alpha was calculated to establish internal consistency for both the FATCOD and the Palliative Care Quiz. In addition, the reliability of the questionnaire was further tested through conducting pretesting of the tool with all Head of Department Nurses from all three settings. No major changes were made to the tool and the data were included.

4.5 Data Collection

Data collection is the "precise, systematic gathering of information relevant to the research purpose" (Burns & Grove, 2009:43). Prior to commencing with data collection, written permission was obtained from the management of the different oncology settings that participated in the study (Appendices C-F). Upon gaining entry into the hospitals, the researcher approached the respondents with the assistance of the Professional Nurse in charge. Meetings were scheduled with the Oncology Nurses in the different settings, during which the researcher personally explained the purpose of, and the procedures involved in the study (Appendix J). The researcher met with the respondents from March 2017 to June 2017, to discuss how to complete the questionnaire in each of the three hospitals (Appendices G and H).

This was done with staff on both shifts, day and night duty. The participants were briefed on the purpose, the nature and the objectives of the study. This was done before they signed the consent form (Appendix K). Their rights as participants were explained before they signed the consent form, so that they could decide if they were willing to be part of the study. The researcher allowed time for questions from respondents in order to eliminate any uncertainties. During these meetings, the information leaflet and consent form were handed out, and written consent was obtained from the respondents (Appendix H). These consent forms were collected separately from the questionnaires, in order to ensure anonymity. Consistency of data collection is critical in order to ensure the validity of the study (Burns & Grove, 2009:441).

It is therefore important to administer the questionnaires in the same manner to all respondents. Hence, the researcher administered all the questionnaires in this study in person to all the respondents in the different oncology settings. The data collection instruments (Appendix L) were handed to each participant and a timeframe of one week was given for the respondents to complete the process. The researcher explained the purpose of this study to the emergency Professional Nurses in the Emergency Departments, and the Oncology Nurses in the Oncology Departments. The information leaflet, consent form and a questionnaire were handed to each of the participants, whilst a timeframe of one week was provided, during which the participants had time to complete the questionnaire.

Issues of confidentiality were addressed and the researcher ensured that confidentiality agreements and informed consent were watertight for the entire duration of the study, and during the process of data cleaning. After completion of the questionnaire, each participant placed the questionnaire into a sealed envelope provided by the researcher, and returned it to the researcher. After one week had elapsed, the researcher returned to collect the questionnaires and placed them securely under lock and key.

4.6 Data Analysis, Management and Methodological Rigor of the Study

IBM SPSS statistical analysis software version 24 (IBM Corp, Armonk, NY, USA) was used for data analysis and management. The data were entered and analysed in SPSS v24. Summary statistics were used to describe the demographics and to summarise the familiarity with and use of various clinical and psychosocial guidelines. A total score for each correct answer was calculated for the Knowledge Score using the Palliative Care Quiz. For the FATCOD, positive items were scored from 1 (strongly disagree) to 5 (strongly agree). Scores were reversed for negative items. Possible scores ranged from 30-150. A higher average score indicates a more positive attitude toward caring for this patient population. Data are presented by means of tables, pie charts and bar graphs. Data management and backup of computer records were performed throughout the analysis process. The data were also stored on a computer secured by passwords.

The completed questionnaires were kept in a safe cabinet, which was vital for backup and security reasons. To assess the rigour of a study, there is a review of the procedures used in achieving results that are credible and accurate (Burns & Grove, 2003). The measures used in achieving results for qualitative and quantitative studies differ. Quantitative rigours involve adhering to a disciplined and diligently followed design to achieve quality findings. Qualitative measures include reliability and validity data as part of an independent process consisting of identifying, analysing and reporting.

4.7 PHASE 2: PART 1: Semi-Structured In-Depth Individual Interviews

4.7.1 Design

Semi-structured in-depth individual interviews were conducted at two of the three Western Cape Province government hospitals. Thus, three patients at Groote Schuur Hospital (GSH) and six at Tygerberg Hospital (TBH) since Victoria Hospital (VH) has a Palliative Care Unit, but not an Oncology Out-Patients Department (OPD). The interviews were conducted with the patients in the Oncology Department and not in OPD. VH patients attend GSH for follow-up.

This was done to address *Objective 2:* To explore the experiences of Oncology Patients regarding palliative care nursing practices in three selected hospitals. In semi-structured interviews, an attempt was made to understand how individuals experience palliative care and whether the core components of person-centred care are part of the patients' experience, the core components being minimizing vulnerability, maximizing control, sharing information and participating.

4.7.2 Sampling of Participants

Purposive sampling is described as a method of deliberately selecting individuals, settings or events in order to provide rich information that may be difficult to obtain from other sources (Burns & Grove, 2003). Sampling is the process of selecting a portion of the population (people, events and behaviours) to represent the entire population. A sample is a small portion of the population that is selected for a particular study (Burns & Grove, 2003).

Purposive sampling was used to select the participants for this study. Purposive sampling is a type of non-probability sampling which is based on the judgement of the researcher, to select a sample that contains the most characteristic and representative attributes of the population, and that serves the study population best (Brink ,2007). The use of purposive sampling allowed the researcher to use her knowledge and expertise regarding the study population to select participants who yielded insights and rich information about the purpose of the study (Brink, 2007).

The choice of such a sampling method is consistent with the exploratory nature of the study, which is not intended to generalise about large populations. In this instance, the researcher selected participants based on inclusion criteria and her personal judgements about which participants would be most representative in relation to the research. The purposive sampling was selected for discharged adult cancer patients attending the Oncology Out-Patient Department in the three selected Western Cape Provincial Hospitals. The participants were carefully recruited applying inclusive criteria. Only participants who met the criteria, had the experience and the ability to share invaluable information, were selected.

Appropriateness and adequacy of data were taken into consideration (Brink, 2007), i.e., the selection of participants knowledgeable about the research. The process of sampling in a qualitative study is a continuous planning decision and there is no fixed number of participants, because the sampling continues until saturation occurs, i.e., when there is a repetition of ideas and views. The researcher did consider the patient's condition and if they were not feeling well at the time of the interview and an alternative date was agreed upon with the patient. The researcher continued with the semi-structured in-depth interview until the process had run its course, and no new ideas were forthcoming, or until data saturation was obtained, or until the point of data redundancy had been reached (Lincoln & Guba, 1985). Participants were purposively sampled at the Out-Patients Department during their routine visits and consultations. No patient was coerced to participate.

- **Inclusion criteria**: Adult cancer patients admitted in the Oncology Wards.
- **Exclusion criteria**: The researcher excluded paediatric Oncology Patients. The researcher also excluded patients who were not feeling well at the time set for the interview.

4.7.3 Member Checking and Verification

Member checking was done with both the Oncology Patient and their families to provide feedback of the recording analysis and to verify the identified themes. A month after the completion of the recoding, the researcher visited the hospitals again to provide verbal feedback of the analysis of the findings, and of the themes that had emerged from the focus group discussion (FGD) and the semi-structured interviews. The verification group discussion lasted less than one hour.

4.8 Findings

Of the Oncology Patients between April 2017 and September 2017, 10% of all hospitalised patients were categorised as palliative care patients (n=25). Of these Oncology Patients, 10% were male and 90% were female. The patients' average age was 53 years (range: 22-70 years). Data collection was done until data saturation was reached.

4.9 Data Collection and Pilot Interviews

Pilot interviews were conducted with two participants from two of the health institutions. Both were operational managers of Trauma and Oncology Nursing Departments. The participants were purposefully interviewed using a semi-structured individual interview method and an interview schedule. Confidentiality was emphasised and reinforced during this research process, in the interviewing of the Oncology Patient as this stage entailed data collection. Data cleaning is the creation of a “clean data” set that does not contain the information of the identified participants, for example, their names or addresses (the researcher identified the information, which was stored in separate protected files). The researcher further ensured that discussing confidentiality at the outset was necessary to build trust with the participants, and acted on this conviction. The researcher made sure that the Oncology Patients participated in an environment of complete confidentiality so that they would feel completely free to express their true feelings and opinions without fear of disapproval from the interviewer. Participants were only selected if they were feeling well enough to do so.

If they were feeling unwell at the time of the interview, an alternative date was established. The interviews at no time interfered with their therapy sessions at the hospital. Rapport did correlate highly with understanding in semi-structured interviews. Language and cultural differences, and language and cultural values are very important factors that have to be taken into consideration by the researcher—to prevent potential misunderstanding and biases which could have detrimental implications for data collection (Burns & Grove, 2007:340). With this in mind, the moderator orientated and briefed an interpreter that was available to assist with any language difficulties experienced by the patients.

4.10 Data Analysis

Interview sessions were tape recorded and transcribed. Detailed hand-written field notes were taken and observations were documented to complement the transcriptions. Tape recordings and dictation were transcribed to text before they were subjected to the same processing as notes.

Transcriptions were coded by the researcher and checked by a second coder. Transcriptions were read and re read for themes and the readers processed the documents to focus on pinpointing, examining, and recording patterns (themes) within data. Themes are patterns across data sets that are important to the description of a phenomenon, and are associated with a specific research question. The themes became the categories for analysis. Thematic analysis was effected through the process of coding in six phases to create established and meaningful patterns. These phases were familiarisation with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report. The transcriptions were also analysed by a second coder. The interview scripts were then processed to edit out the names of the participants. However, the personal identifiers such as the contextual identifiers in individual life stories remained (Guillemin & Gillam, 2004).

4.11 PHASE 2: PART 2: Focus Groups Interviews

The Objectives of Part 2: to explore the experiences of the family of the Oncology Patient in current palliative care nursing practices in three selected Western Cape Provincial hospitals, a focus group discussion (FGD) was held with family members of patients. A focus group interview is a 'purposive discussion of a specific topic or related topics taking place, between eight to ten individuals with a similar background and common interests' (Watson, McKenna, Cowman & Keady; 2008).

The choice of focus group interviews as a data collection method was because all of the participants were family members of the Oncology Patients in the hospital and involved in their care at home. They were selected because of their ability to contribute to the understanding of their experience in the hospital. The focus group interviews for the family participants were held at two of the selected government hospitals. Permission to use venues on site was obtained from the hospital managers after the family members had been identified. Focus group interviews were conducted during June and July 2017. A total of five focus groups at two of the government hospitals were held. = 5 Focus Group Discussions

4.11.1 Sampling of Participants

The purposive sampling method was employed by purposively selecting family members of the Oncology Patient who accompany Oncology Patients to the Out-Patients Department. The participants were drawn from two of the three hospitals. The participants were carefully recruited applying inclusive and exclusive criteria. Focus groups for families consisted of family members. Each group had not more than 12 and not less than 6 participants. There was one group per hospital until data saturation occurred. One pilot focus group interview was conducted at one of the government hospitals.

4.11.3 Inclusion and Exclusion Criteria

- **Inclusion criteria**: Adult family member who accompanies and is directly involved in the care or support of the patient.

- **Exclusion criteria**: Children (under the age of 18) who accompanies the patient.

At each of the two (of three) selected government hospitals there was one family focus group. = 2 focus groups

4.11.4 Description of the Family of the Oncology Patient

The family caregivers presented between the ages of 22 and 65 years. There were ten (10) females (two wives, four daughters, one daughter-in-law, three mothers,) three males out of which, two sons (who were the caregivers, =13 participants .Their activities ranged from teacher, to social worker, to self-employed. Of the family participants interviewed six (6) resided in the Western Cape Metro, and seven (7) resided in the Overberg region.

4.11.5 Preparation of the Field for the Focus Group Discussion for the Family

After the researcher had identified participants, the researcher made appointments with them, scheduling them for a convenient time chosen by them. The FGD was held after consultations with the physicians and checking the dates and times of clinic consultations. A comfortable office was assigned for the FGD, the setting had no distractions and was conducive to interaction (Watson, McKenna, Cowman & Keady; 2008). Although the office was within the hospital structure, it was located out of earshot of passers-by, thus enabling the participants to share their experiences without feelings of unease. The seating arrangement allowed face-to-face interaction that facilitated observation and enhanced communication. Through the focus group discussion sessions, the researcher has to know the participants as they described their experience of palliative care (Babbie & Mouton, 2009).

4.11.6 Procedure of the Focus Group Discussion

Permission was obtained from the participants to audiotape the discussion. The participants were required to sign a voluntary participation and focus group confidentiality binding form prior to the commencement of the focus group discussion. The researcher gathered 5-9 family participants in a room within the Oncology Department, with a moderator to discuss one or more issues, for approximately 45 minutes. All the participants were encouraged to participate fully in the group discussions.

The participants were informed that there were no right or wrong answers and assured that all their contributions were valuable. The objectives of the study guided the questions that were asked. A pilot study was conducted and changes were effected on the recommendations of the participants. The data from the pilot study were included during the data analysis process. Each focus group interview was guided by broad research questions.

Probing comments or questions were used to steer the discussions and to clarify aspects that were unclear to the researcher (Paton, 2002). Verbal prompts such as ‘uh-huh’ and non-verbal cues such as head nodding were used to encourage participants to continue talking. The purpose of the research and the research process of the FGD were explained to the participants. Consent forms were signed and the participants further consented verbally to be part of the study. The researcher introduced the secretary who was to tape record the sessions.

Rapport was established between the researcher and the participants to increase a participant-researcher interaction that fostered trust and enabled free flowing communication. The researcher then assigned herself as the moderator for the FGD. The moderator introduced issues and ensured that no one person dominated. The moderator was flexible, kept participants on the topic and encouraged discussion.

A psychologist was made available for any participants who needed support immediately after the focus group interview after sharing information about their family member that may be sensitive to them. Responses were tape-recorded by a secretary who assisted the moderator. An interpreter was guided by the moderator at each of the focus group sessions to translate if there were any language difficulties on the part of participants. The duration of the focus group discussion did not exceed an hour. The physical environment was fully functional with audio recorders, a notebook, spare batteries and a signed consent form.

At the end of focus group interviews, the researcher briefly summarised the main points of the interview and sought verification from the participants. All the participants were thanked for their participation at the end of the session. The total number of FGDs and unstructured interviews conducted in this study was determined by data saturation. To ensure trustworthiness of the collected data, Guba & Lincoln’s (1985) strategies of credibility, transferability dependability, confirmability and authenticity were applied.

Part 2 of the process included two qualitative studies, namely, a focus group with the family of the patients. In Phase 2 of the study, a total of four (n=4) FGDs were conducted in two of the three government hospitals, among 25 participants between the ages of 25 and 55 years. Each group consisted of 4-5 participants and the interviews did not exceed one hour per session. The discussions were tape-recorded and field notes were taken. The data were analysed using standard qualitative data analysis techniques and the field notes were checked for agreement of all the participants on the findings, which were tape-recorded and documented.

4.12 PART 3: Palliative Care Protocol Development

The aim of Part 3 was to develop a palliative care protocol as specified for **Part 3** of the process**:** the development of palliative care protocols using the Nominal Group Technique. This technique was used by integrating the data collected in Parts 1, 2 and 3, and information from the literature review, with information gathered from the Emergency and Oncology Nurses working in the Emergency and Oncology Departments, and information gathered from Oncology Patients and their families in the three selected Western Cape Provincial Hospitals. This phase was done through the two qualitative studies. Focus group discussions with family members and semi-structured interviews with patients in palliative care were carried out. To address the knowledge, attitudes and practices of the Emergency and Oncology Nurses, questionnaires were administered. Key concepts were identified for the model to generate the guidelines for palliative care protocol development.

4.12.1 Qualitative Data Analysis

Data analysis involved data reduction, organisation and subsequent interpretation using themes (Burns & Grove, 2003:479). The researcher translated and transcribed the tape-recorded interviews, and then read and reread the transcripts in their entirety, reflecting on the interviews as a whole. The interviews were summarised, keeping in mind that more than one theme might emerge from a set of interviews (Morse & Field, 1996).

4.12.2 Description

The descriptive stage is more critical in qualitative studies. It is the initial phase whereby the researcher becomes familiar with the data (Burns & Grove, 2003). In this study, the researcher replayed the tape after the interview to listen to voice, tone and responses; attention was paid as much to pauses as to what was said. The data collected from the focus groups were analysed the same way as for the data collected from qualitative studies. However, the researcher was cautious about data from focus groups, since these were complex, and resulted in analysis being required at several levels. The analysis had to take into account various responses given by the same person, responses among people in the same group, and a comparison of responses in different groups (Burns & Grove, 2007:379). Probing was done by the researcher only when necessary, to further open up discussion and plumb topic areas. It was thus important to attend to the degree of consensus and interest in the topic generated in the discussion. The moderator required the interpreter to be available if there were language difficulties at any of the focus group discussions.

After transcribing the discussion, the researcher replayed the tape to correlate the information for accuracy (Streubert & Carpenter, 2003). To uncover the meaning of the experiences, the researcher read the interview transcripts several times. In so doing, the researcher explored personal feelings and experiences that could influence the study, and integrated this understanding and feeling into the study—this is known as “reflective thoughts” (Burns & Grove, 2003:382).

Transcriptions were read and reread for themes. The themes became the categories for analysis. Thematic analysis was carried out through the process of coding in six phases to create established, meaningful patterns. These parts were: familiarization with data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and producing the final report (Tesch, 1990).

The transcriptions were also analysed by a second coder. Coding was used to expand, transform and re-conceptualise data, providing opportunities for more diverse analyses. Memos were used to record insights or ideas related to notes, transcripts or codes. The researcher recorded any ideas that emerged even if they were vague or not well thought out. Memos were given titles and provided with dates.

4.12.3 Interpretation

Interpretation focused on the usefulness of the findings for clinical practice or moved toward theorizing. These tentative propositions were sorted into categories (Burns & Grove, 2003).

4.13 Validity and Reliability of Qualitative Research

The model for trustworthiness in qualitative data must be upheld as identified by Guba (1981) in (Lincoln & Guba, 1985). The model describes the following criteria: credibility, dependability, confirmability, transferability and authenticity.

4.13.1 Credibility

Polit & Beck (2012:585) and Lincoln & Guba (1985) viewed credibility as the overriding goal of qualitative research. Credibility refers to confidence in the truth of the data. The study needs to be believable and steps need to be taken to demonstrate this. The following strategies were used to ensure the credibility of the study. Observation notes were taken during the interviews to strengthen the data. There were full descriptions of the interview process and techniques, and FGDs that involved probing, including member verification.

4.13.2 Dependability

Brink, Van Der Walt & Van Rensburg (2012) stated that the term dependability refers to the stability of the data over time. The researcher maintained accurate records of all the steps followed and ensured dependability in this study, in that it was conducted in a manner that enabled the researcher to retrace all the research steps.

4.13.3 Confirmability

Refers to objectivity or neutrality of the data obtained (Polit & Beck, 2012:723). Confirmability ensures that the data reflect the participants’ voices and not the biases of the researcher.

4.13.4 Transferability

Refers to the ability to apply the findings in other contexts or to other participants (Brink et al., 2012:173). It is the responsibility of the researcher to provide sufficient descriptive data in the research report, to enable others to evaluate the applicability of the findings of other contexts

(Lincoln & Guba, 1985). Purposive sampling increased transferability since the sample criteria were specified and information-rich participants were chosen. The presence of similar responses by participants increased transferability.

4.13.5 Authenticity

According to Polit & Beck (2012:720), authenticity refers to the extent to which researchers fairly and faithfully show a range of different realities in the collection, analysis and interpretation of data. Authenticity was ensured by using quotes from the participants interviewed to describe their experiences in the final report.

4.14 Ethical Principles and Considerations

The following clearances, permissions, consents and approvals were obtained before the commencement of this study:

- Ethical clearance from the Senate Higher Degrees Committee and Senate Research Committee of the University of the Western Cape, South Africa.
- Approval and permission from the National Research Foundation of South Africa.
- Permission and approval from the Research Ethic Boards of Groote Schuur, Tygerberg and Victoria Hospitals.
- Permission from the Nursing Managers and Operational Managers of Groote Schuur, Tygerberg and Victoria Hospitals.
- Informed consent was obtained from the participants for all phases of the study.

4.14.1 Permission

Prior to commencement of the research, approval was obtained from the Behavioural Research Ethics Committee at the University of the Western Cape (Appendix A). Thereafter, the researcher applied in writing for consent for the research site and participants of the research, from the research gatekeeper of the Provincial Administration as well as the Western Cape hospitals selected for the research (Appendices B-F). After each information session with the participants (Appendices G and J), the purpose and protocols of the research were explained by the researcher and written consent obtained for participation throughout, and at every phase of the research. The process of informed consent was given enough time, so that each participant was able to ask questions. Each participant was requested to sign an informed consent form (Appendices H and K), and was told that they were free to withdraw from the research at any time. To uphold and to protect the rights of each of the participants, the following ethical considerations were adhered to in the implementation and throughout the research.

4.14.2 Participants

Fair selection of participants, i.e., fairness in the selection of the research population and of participants, in particular. Therefore, the selection of the participants followed the inclusion criteria. The sample was drawn, regardless of race, social status or any organisational affiliations. If participants were unwell, they were rescheduled for a time when they were feeling better.

4.14.3 Consent

Consent was requested from each of the participants and they were informed of the nature and the intention of the research (Appendices G-K).

4.14.4 Confidentiality

All the information was treated with strict confidentiality and used solely for the purpose of research. The confidentiality of the data maintained by using codebooks and other techniques to conceal and protect any identifying information.

4.14.5 Anonymity

Anonymity was ensured throughout the research. The questionnaire and the interview required that no names of respondents be used. The participants were informed that their reports would not harm any person in any way.

4.14.6 Voluntary Participation

Participation was voluntary and there was no obligation, the participants were informed of the right to withdraw from any process at any phase of the research, without prejudice. The researcher was available at all times for consultation with the participants throughout the duration of this study. In addition to the above, the protection of the terminally ill patients' human rights is a very important ethical principle that was at all times adhered to by the researcher.

4.14.7 Right to Self-Determination

Respect was demonstrated for the ethical principle of personal autonomy, i.e., that humans are capable of controlling their own identity. The patients as humans have the right to be treated as autonomous agents to choose without external controls. They were allowed to choose whether they wish to participate or to withdraw at any time without penalty.

4.14 8 Autonomy and Persons with Diminished Capacity

At all times the researcher upheld only the best interests of the patients, as these patients are vulnerable due to their terminal condition. These patients required additional ethical protection of their right to self-determination because of their decreased ability or inability to give informed consent. In addition, these patients were vulnerable to possible coercion and deception. The research report included justification for the use of patients with diminished autonomy, and access to patients at risk and increased vulnerability. If the patient was feeling unwell on the day, the researcher set another date when the patient felt better.

The researcher assured the Oncology Patients as participants of complete confidentiality so that they would feel completely free to express their true feelings and opinions without fear of disapproval from the interviewer. The researcher ensured that a psychologist or psychiatrist was available for any emotional or psychological support for patients during any time of the interview—pre-and post-interview emotional and psychological support was readily available. Rapport correlated highly with understanding in unstructured interviews.

4.15 Summary

In Chapter 4, the research methodology was discussed in detail, with reference to the overall quantitative and qualitative phases, and the three parts leading to the development of a palliative protocol for the government hospitals of the Western Cape, South Africa. Steps to ensure rigour and ethical considerations were discussed. The data analysis and the initial interpretation of the data will be discussed in Chapter 5.

CHAPTER 5

ANALYSIS AND INTERPRETATION OF THE QUANTITATIVE DATA

5.1 Introduction

In this chapter, the analysis of the quantitative data obtained during this study is discussed. The overall aim of the study was to develop applied palliative care protocols for Emergency and Oncology Nurses to provide best practice palliative care nursing for Oncology Patients who may present at of the Groote Schuur, Tygerberg or Victoria Western Cape Provincial Hospitals. Objective 1 was to investigate the knowledge, attitudes and practices of the Emergency and Oncology Nurses regarding palliative care nursing practices/procedures for Oncology Patients in three of the Western Cape Provincial Hospitals.

The findings from the quantitative objective 1 will inform the qualitative study. The qualitative data was collected to address Objective 2, which was to explore the experiences of the Oncology Patients, and their families regarding delivery of current palliative care nursing practices in three of the Western Cape Provincial Hospitals. This chapter reflects the findings of Part 1: a quantitative survey using questionnaires to investigate the palliative care knowledge, attitudes and practices for the Emergency and Oncology Professional Nurse. A convenience sample of 102 participants was included in the study, comprising of participants from three government hospitals. A total of 56 respondents completed and returned their questionnaires, whilst no responses were obtained from the remaining 10 participants. The response rate of 75.15% was thus satisfactory.

5.2 Data Analysis Method

Data analysis is the organisation of the raw data in order to present them in a way that will provide answers to the research questions (Brink, 2006:170). Analysis of quantitative data were done by using statistical strategies. Descriptive statistics summarise the data whilst inferential statistics allow inferences to be made about the population of the study (Brink, 2006:171). Probability values (p values), with a significance level of 0.05, were used to determine the significance of the findings. Probability refers to the chance that an event can be accurately predicted, or that particular outcome that will result from a certain action (Burns & Grove, 2007:406). The raw data were first captured on MS Excel, followed by the SPSS 24 software system used to analyse the data.

The descriptive statistics used to describe the variables included frequency distributions in the form of bar charts, pie charts and frequency tables, measures of central tendency and standard deviations. The standard deviation (SD) is the 'average difference or deviation value' and provides a measure of the average deviation of a value from the mean in a sample (Burns & Grove, 2007:418). The means is the 'sum of all the scores, divided by the number of scores' (Burns & Grove, 2007:417) whilst the 'score at the exact centre of an ungrouped frequency distribution' is called the median.

5.3 Description of Statistical Analysis

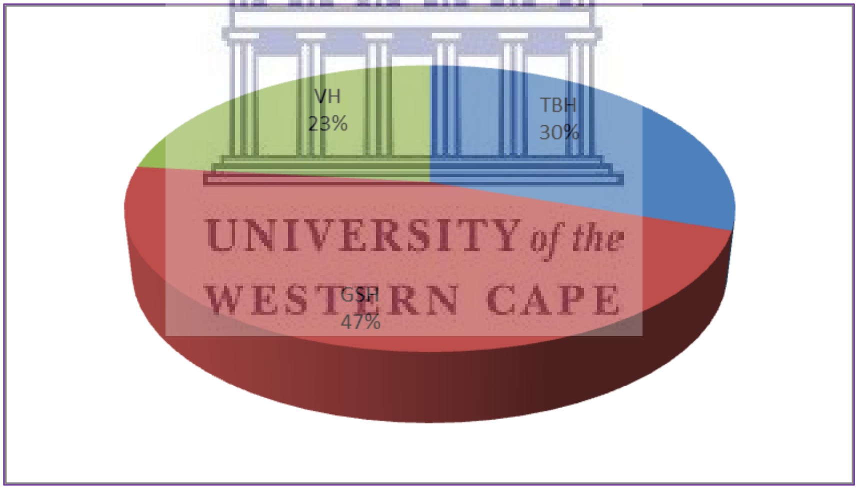
The data generated were analysed and presented in the form of frequency distribution tables, bar graphs and pie charts. Analysis included the calculation of the mean, median and standard deviation. The mean value is the average value for the variable, while the median refers to the middle value when the values are arranged from the smallest to the largest. If the median is larger than the mean value, then most of the values will be found above the mean value. The standard deviation is an indication of how closely values are clustered around the mean (Burns & Grove, 2002:418).

The p-value is the measure reported for all tests of statistical significance. It is defined as the probability that an effect, at least as extreme as that observed in a particular study, could have occurred by chance alone. If the p-value is greater than 0.05, by convention, the chance cannot be excluded as a likely explanation and the findings are stated as statistically insignificant at that level. If the p value is less than 0.05, it is considered significant. Therefore, the 95% confidence interval was applied to determine whether there would be an association between the variables. The Spearman rank correlation coefficient was used to determine the degree of the relationship between two ordinal variables and is expressed with the symbol r (Brink, 2006:180).

5.4 SECTION A: Demographics of the Respondents – Sample Realisation

5.4.1 Work Distribution of the Respondents at Government Hospitals

The government hospitals selected for this research provided the information regarding the palliative care nursing practices and procedures for Oncology Patients in the Western Cape. Figure 5.1 shows that the majority of the respondents (47%) worked at Groote Schuur Hospital (GSH), 30% worked at Tygerberg Hospital (TBH) and 23% worked at Victoria Hospital (VH).



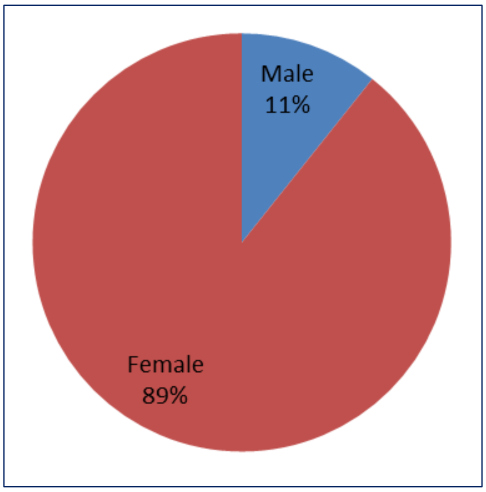
n=56; **GSH:** Groote Schuur Hospital; **TBH:** Tyberberg Hospital; **VH:** Victoria Hospital

Figure 5.1: Work distribution of the respondents at government hospitals

5.4.2 Gender Distribution of the Respondents

Figure 5.2 indicates that female respondents made up 89% and male respondents 11% of the study sample. The shortage of males in the study can be attributed to the longstanding tradition that nursing is a female profession. The current research data are in agreement with those reported by

Dunn et al. (2005:101) that nursing remains a female-dominated profession.



n=56

Figure 5.2: Gender distribution of the respondents

5.4.3 Age Distribution of the Respondents

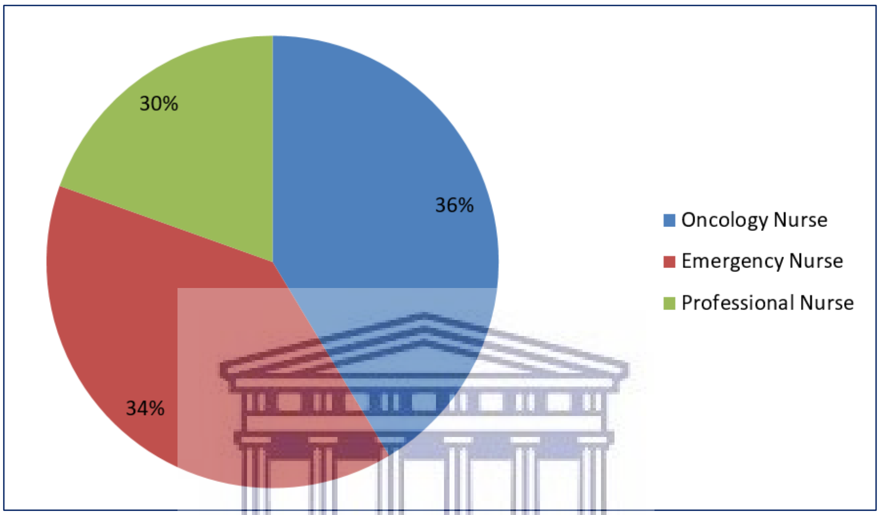
Table 5.1 shows that most of the respondents in the research study were in the 26-30 year old age range. According to Dunn et al. (2005:101), age does influence attitudes towards caring for patients who are dying with older nurses displaying more attitudes that are positive in this regard.

Table 5.1: Age distribution of the respondents

Age of respondents	**Number (n)**	**Percentage**
20-25	6	10.5
26-30	14	24.5
31-35	4	7.0
36-40	4	7.0
41-45	4	5.3
46-50	5	8.8
51-50	6	10.5
56-59	12	22.8
60 and over	1	1.8
Total	**56**	**100**

5.4.5 Workplaces of the Respondents

The majority of the respondents (n=20; 36%) worked in Oncology Units, whereas some (n=19; 34%) worked in Emergency Departments and others (n=17; 30%) worked in Emergency Wards (Figure 5.3). Abeit & Jones (2007:737) indicated that the workplace might have a direct influence on Professional Nurses' attitudes towards caring for patients who are dying.



n=56

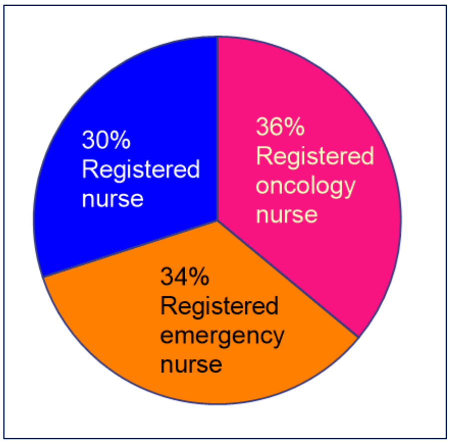
Figure 5.3: Workplaces of the respondents

5.4.6 Professional Rank of the Respondents

There was almost an equal balance of professional rank of the respondents in that 36% of the respondents were Registered Oncology Nurses, 34% were Registered Professional Emergency Nurses whilst 30% were Registered Professional Nurses (Figure 5.4). The professional rank of the respondents varied—the majority (36%) worked in the Oncology Wards and Oncology Out-Patients Department. Currently, a one-year postgraduate training in Post-Basic Oncology and Emergency is offered at the Government Nursing College in the Western Cape.

5.4.7 Experience of the Respondents in Oncology and Emergency Departments

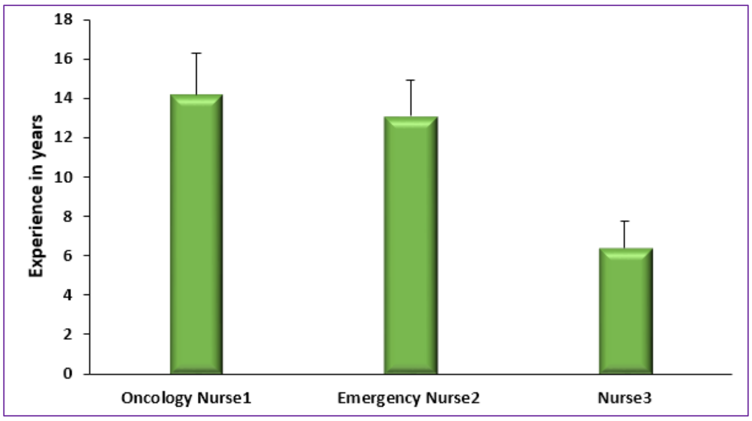
Figure 5.5 indicates that an equal proportion of respondents had either an average of 14.2 years (n=20; 35.71%) experience in Oncology Department or an average of 13.1 years (n=19; 33.93%) in the Emergency Department.



n=56

Figure 5.4: Professional rank of the respondents

The maximum number of years of experience in Oncology were 34 years and the minimum number was 1 year, and most respondents had 8 years' experience (i.e., mode=8 years) in oncology. The maximum number of years of experience in Emergency were 30 years and the minimum number was 2 years, and most respondents had 10 years' experience (mode=10 years) in emergency. It is acknowledged that the greater the number of years of experience, the better the quality of nursing care that is provided to patients (Mok & Chiu, 2004).



n=56

Figure 5.5: Experience of the respondents in oncology and emergency nursing

5.4.8 In-Service Training in Trauma and Oncology

In-service training in Trauma and Oncology in the last 12 months was provided to 43% of the respondents whereas 57% had not received it (Figure 5.6).

5.4.9 Ratings of the Effectiveness of the Referral Pathways in Hospitals

Questions 8-10 rated the effectiveness of the referral pathways in their hospital. The response was varied as reflected in Figure 5.7, i.e., the pathways between Emergency Department and the Ward, Emergency Department, the Out-Patients Department and the Ward and the Out-Patients Department. The rating for each area was good, could be improved or poor.

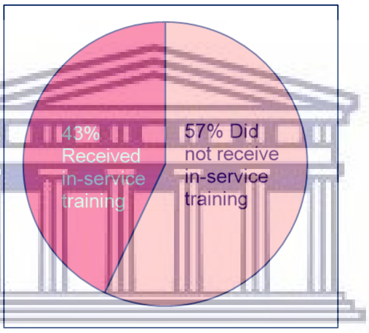


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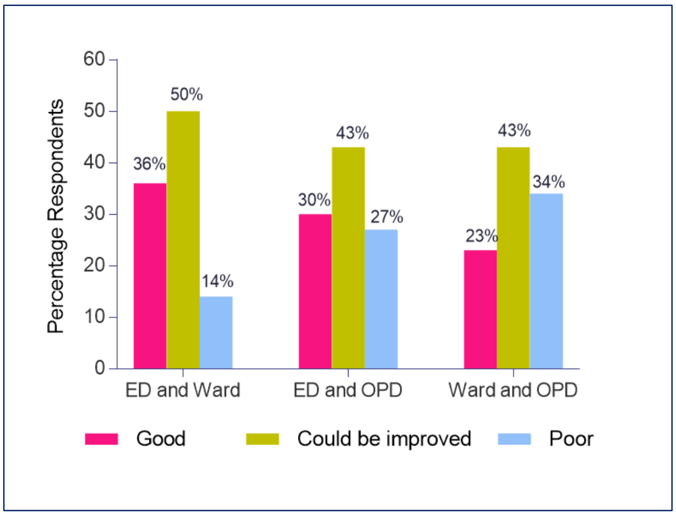
Figure 5.6: In-service training in trauma and oncology received by respondents

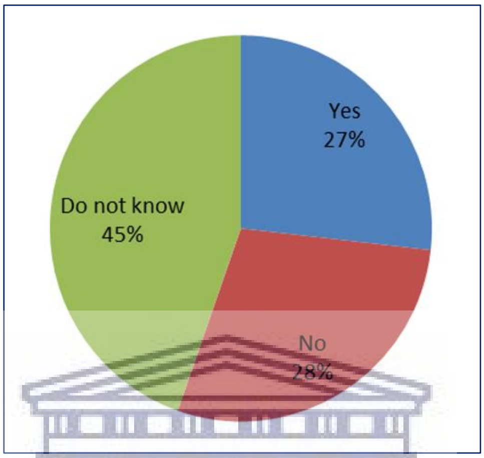


n=56; **ED:** Emergency Department; **OPD:** Out-Patients Department

Figure 5.7: Respondents’ ratings of the effectiveness of the referral pathways in hospitals

5.4.10 Understanding of MOU between Emergency Department and Oncology Services

Of the total number of respondents (n=56; 100%), some (n=15; 27%) indicated yes, while others indicated no (n=16; 28%) or that they did not know (n=25; 45%) of a Memorandum of Understanding (MOU) between ED and the Oncology Services.



n=56

Figure 5.8: Respondents' understanding of MOU between Emergency Department and Oncology Services

5.5 SECTION B: Knowledge of the Emergency and Oncology Nurse

The questions related to the knowledge of the Emergency and Oncology Nurses. The respondents either had to indicate they know, false or did not know. A total score of correct answer was calculated for the Knowledge Score using the Palliative Care Quiz.

5.5.1 Presentation of Responses Recorded on the Questionnaires

Table 5.2 summarises the responses recorded on the questionnaires.

5.5.2 Analysis of Responses Recorded on the Questionnaires

Analysis of the Responses Recorded on the Questionnaires is provided in the context of literature reports on the various responses indicated to the questions. An asterisk (*) denotes the appropriate response to the question.

Table 5.2: Summary of responses recorded on the questionnaires

Knowledgeable	Response	n	Marginal Percentage
Palliative Care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration	True	26	46.4%
	False	28	50.0%
	Do not know	2	3.6%
Morphine is the standard use to compare the analgesic effect of other opioid's	True	33	58.9%
	False	19	33.9%
	Do not know	4	7.1%
The extent of the disease determines the method of pain treatment	True	34	60.7%
	False	19	33.9%
	Do not know	3	5.4%
Adjuvant therapies are important in managing pain	True	37	66.1%
	False	4	7.1%
	Do not know	15	26.8%
It is crucial for family members to remain at the bedside until death occurs	True	30	53.6%
	False	21	37.5%
	Do not know	5	8.9%
During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation	True	29	51.8%
	False	12	21.4%
	Do not know	15	26.8%
Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain	True	26	46.4%
	False	25	44.6%
	Do not know	5	8.9%
Individuals who are taking opioid's should also follow a bowel regime	True	45	80.4%
	False	6	10.7%
	Do not know	5	8.9%
The provision of palliative care requires emotional detachment	True	24	42.9%
	False	27	48.2%
	Do not know	5	8.9%
During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate in the treatment of some types of pain	True	29	51.8%
	False	17	30.4%
	Do not know	10	17.9%

Men generally reconcile their grief more quickly than women	True	11	19.6%
	False	30	53.6%
	Do not know	15	26.8%
The philosophy of palliative care is compatible with that of aggressive treatment	True	14	25.0%
	False	27	48.2%
	Do not know	15	26.8%
The use of placebos is appropriate in the treatment of some types of pain	True	16	28.6%
	False	18	32.1%
	Do not know	22	39.3%
In high doses, codeine causes more nausea and vomiting than morphine	True	19	33.9%
	False	23	41.1%
	Do not know	14	25.0%
Suffering and physical pain are synonymous	True	29	51.8%
	False	16	28.6%
	Do not know	11	19.6%
Demerol is not an effective analgesic in the control of chronic pain	True	17	30.4%
	False	13	23.2%
	Do not know	26	46.4%
The accumulation of losses renders burnout inevitable for those who seek work in palliative care	True	32	57.1%
	False	13	23.2%
	Do not know	11	19.6%
Manifestations of chronic pain are different from those of acute pain	True	47	83.9%
	False	7	12.5%
	Do not know	2	3.6%
The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate	True	40	71.4%
	False	15	26.8%
	Do not know	1	1.8%
The pain threshold is lowered by anxiety or fatigue	True	18	32.1%
	False	30	53.6%
	Do not know	8	14.3%
Total		**56**	**100.0%**

- Question 9: Palliative Care is deemed appropriate only in situations where there is evidence of a downhill trajectory or deterioration.

True
False*
Did not know

According to the Palliative Care Services Guidelines published by Health and Welfare Canada (1989), individuals receiving aggressive treatment cancers where the hope for cure is diminished, these patients may receive the supportive aspect of palliative care from the beginning at the time of the diagnosis. This care may lessen as treatment is successful and to sustain a reasonable QOL (Doyle et al., 1993).

- Question 10: Morphine is the standard used to compare the analgesic effect of other opioids.

True*
False
Did not know

The uses of morphine as the standard against which comparisons are made are classified among opioid analgesics with respect to the dosage and duration of action (Crane et al., 1990).

- Question 11: The extent of the disease determines the method of dosage of pain treatment.

True
False*
Did not know

The severity of the extent of the pain determines the dosage of the drug including the route of administration taking into consideration the patient’s ability to swallow, the presence of bowel obstruction and the inability to handle oral opioids (Coyle, 1990).

- Question 12: In the treatment of pain, adjuvant therapies are important as part of the treatment plan.

True*

False
Did not know

The Oncology Nursing Society (1990) emphasises the importance of using adjuvant analgesics (antidepressants, anti -emetics), including non-drug adjuvant measures, better known as patient education and relaxation in the management and in the control of pain.

- Question 13: It is vital for family members to remain at the bedside until death occurs.

True
False*
Did not know

Assumptions about the importance of family members remaining at the bedside of a patient are complex. According to Kaye (1990), keeping a vigil can become exhausting for the family members. It may be useful for the Professional Nurses to suggest a schedule of family visits so that some family members keep vigil while others rest. Ultimately, it is difficult to estimate how long a semi-conscious patient may live.

- Question 14: During the last days of life, patients may experience drowsiness associated with electrolyte imbalance may decrease the need for sedation.

True*
False
Did not know

During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation. According to Fausinger & Bruera (1990), the decrease of fluids and electrolyte imbalance acts as a natural anaesthetic in the central nervous system resulting in the decreased level of awareness and decreased suffering and consequently a decreased need for sedation.

- Question 15: When morphine is used on a long-term basis, it could lead to drug addiction.

True
False*

Did not know

Patients with chronic pain do not and cannot get addicted to morphine. The pain is abolished even with high doses of morphine used for several months (Kaye, 1990). However, the use of morphine can be stopped with no withdrawal symptoms. Furthermore, cancer patients who are terminally ill can be reassured when morphine is correctly administered addiction would not happen.

- Question 16: Individuals should be taking opioids should also follow a bowel regime.

True*
False
Did not know

The recommendation by Crane et al. (1990) is that all patients receiving analgesics should start with bowel regime. Various reasons were researched, including the actions of narcotics on receptors in the gastrointestinal tract that cause peristalsis and secretions to decrease.

- Question 17: Palliative care requires emotional detachment.

True
False*
Did not know

There is substantial evidence that nurses, patients and families consider good quality care to include both technical and expressive expertise (Bowers, 1987). Nurses highly value time spent with patients—to listen to them the Professional Nurse will support counsel and encourage which is an integral and valued component of nursing and cannot be executed effectively within a context of emotional detachment.

- Question 18: During the terminal stages of an illness, it is appropriate to use drugs that can cause respiratory depression for the treatment of severe dyspnoea.

True*
False
Did not know

Dyspnoea should be treated with opiates in a similar manner to the way opiates are used in pain control as supported by Kaye (1990) in stating morphine reduces the inappropriate and excessive respiratory drive that is a clinical manifestation of dyspnoea.

- Question 19: Men are found to reconcile their grief quicker than woman

True
False*
Did not know

The severity of grief is dependent upon the degree of disruption. Nevertheless, it may appear that women are more vulnerable than men due to their lives being conventionally more bound up in personal relationships, according to (Mc Horney & Moore , 1998). It is also reported within the literature that grief resolution is a gender-neutral process that includes the need to re-establish continuity and to find a way to interpret oneself and the world that preserves the thread of meaning (Marris, 1974). It is further reported that factors other than gender such as the nature of the relationship, age, health and their coping mechanism are vital to achieve a positive outcome following bereavement.

- Question 20: The philosophy of palliative care is found to be compatible with aggressive treatment.

True*
False
Did not know

The provision of palliative care is not necessarily incompatible with the aggressive treatment as supported by Macdonald (1991) who affirmed that the control of pain and other symptoms control may require measurement of psychological, social and spiritual symptoms and the management goes beyond the more supportive measures usually linked with palliative care such as palliative care can be initiated early in the course of the illness in conjunction with anti-cancer therapy.

- Question 21: The use of placebos is found appropriate in the treatment of some types of pain.

True
False*
Did not know

The researcher noted substantial support in the literature regarding the inappropriateness of using placebos in the treatment of pain (McCaffery & Beebe, 1990).

- Question 22: In high doses, codeine causes more nausea and vomiting than morphine.

True*
False
Did not know

McCaffery & Beebe (1990) noted that codeine is relatively more toxic in high does than morphine, causing more nausea and vomiting and considerable constipation.

- Question 23: Suffering and physical pain are linked to each other.

True
False*
Did not know

An important key factor is that suffering is linked to the impact of all symptoms experiences, it is not just the presence of pain and other dimensions of living with an illness, whether the illness is terminal or not.

- Question 24: Demerol is not recommended as an effective analgesic in the control of chronic pain.

True*
False
Did not know

Crane (1990) cautioned never to use Demerol to control chronic pain because of its short duration and the accumulation of toxic metabolites such as Normeperidine. Furthermore, it is very sensitive to use in continuous subcutaneous infusion Kaye (1990).

- Question 25: The accumulation of loss is experienced ultimately to be in situations of burnout that is inevitable for those who work in palliative care.

True
False*
Did not know

Numerous studies document that it is the diffusion, differentiation and tensions within nursing that contribute to problems of burnout and high turnover rather than the accumulation of losses associated with providing care to those who are terminal. The problem of burnout in palliative care are more realistically situated within the context of a work-related environment. According to Baines (1991), the ideology is not easily congruent with an ideal and ethic of care that permeates the professional lives of nurses.

- Question 26: Chronic pain manifestation is different comparted to acute pain.

True*
False
Did not know

Acute and chronic pain manifestations are distinct entities and acute pain is accompanied by the "fight and flight" response to chronic pain that tends to dominate. Chronic pain has the greatest potential for impact on the psychological well-being of the patient (Dicks, 1990).

- Question 27: The loss of a distant or contentious relationship is easier to grief than the loss of one that is either close or intimate.

True
False*
Did not know

It is difficult to predict the outcomes of loss as the working out of bereavement represents a general principle of adaption to life following the death of a husband or wife, child, parent brother (Marris, 1974).

- Question 28: The pain threshold is lowered by anxiety or fatigue.

True*
False
Did not know

The literature is cautious regarding attending to factors that moderate pain sensitivity such as anxiety and fatigue (Jenner, 1991).

5.5.3 Summary of Responses Recorded on the Questionnaires

The above section addressed the knowledge of the Professional Emergency and Oncology Nurse regarding palliative care. Effective measurement of knowledge is an important component of both nursing education and nursing practice (Benner, 1984). The palliative quiz was used to measure the knowledge of the Professional Emergency and Oncology Nurse and to serve a variety of purposes, including the assessment of learning needs and the evaluation of programmes and services.

It is known that there is growing development in palliative care services in providing comprehensive compassionate and competent nursing care to an increasing population of Oncology Patients admitted to the two government hospitals. It is vital that nursing educators and health administrators incorporate a method of measuring the learning needs of the providers of care, including providing instruction to learners and determining quality outcomes-based educational programmes directed at increasing the knowledge of palliative care practice from the admission of the Oncology Patient to the Oncology Ward.

The findings of the palliative care questionnaire recommended that educational programmes in palliative care should be aimed at a specific target group with identifiable learning needs. Nevertheless, given the similarities in misconceptions across groups, there is a need for all levels of Professional Nurses to upgrade and upskill their palliative care knowledge of the concepts. Section C will address the nurses’ attitudes towards caring for the dying.

5.6 SECTION C: Emergency and Oncology Nurses' Attitudes Towards Caring for the Dying

Emergency and Oncology Nurses' attitudes towards caring for the dying will address Objective 1, i.e., to investigate the attitudes of the Emergency and Oncology Nurses regarding palliative care nursing practices/procedures. The reliability of the FACTOD scale was considered acceptable with a Chronbach's alpha of 0.81. On average, the majority of the respondents reported strongly positive attitude towards caring for patients who are dying. On a scale of 1 (not positive) to a scale of 6 (very positive), the median=4.9, mean=4.8 and the standard deviation=0.4. Questions 49-74 relate to the attitude towards caring for the dying.

5.6.1 Giving Nursing Care to the Dying Patient Is a Worthwhile Learning Experience

Figure 5.9 illustrates that 66.1% of the respondents totally disagreed, while 25% of the respondents disagreed that giving nursing care to the dying person was a worthwhile learning experience and 8.9% mildly agreed that it was a worthwhile learning experience. Doyle (1986) was of the opinion that the caring relationship between nurse and patients result in growth for both the patient and the nurse, which can alter the attitude as the relationship, develops between the Professional Nurse, patient and the family.

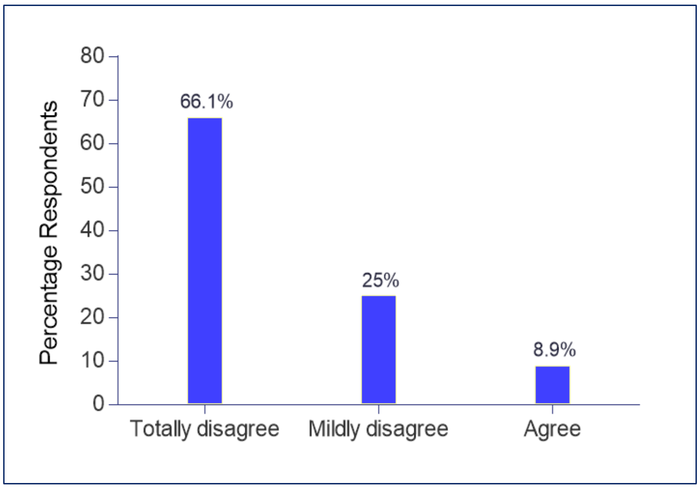


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Figure 5.9: Respondents' attitudes towards dying is a worthwhile learning experience

5.6.2 Death is Not the Worst Thing That Can Happen to a Patient

Figure 5.10 shows that the response categories to agree and disagree were divided regarding this statement with 5.4% strongly agree, 25% agree, 16.1% disagree, 21.4% totally disagree and 1.8% of the respondents regarded the statement as not important. Costello's (2006:597) finding that good and bad death experiences can influence Oncology Nurses positively or negatively may explain this divided result.

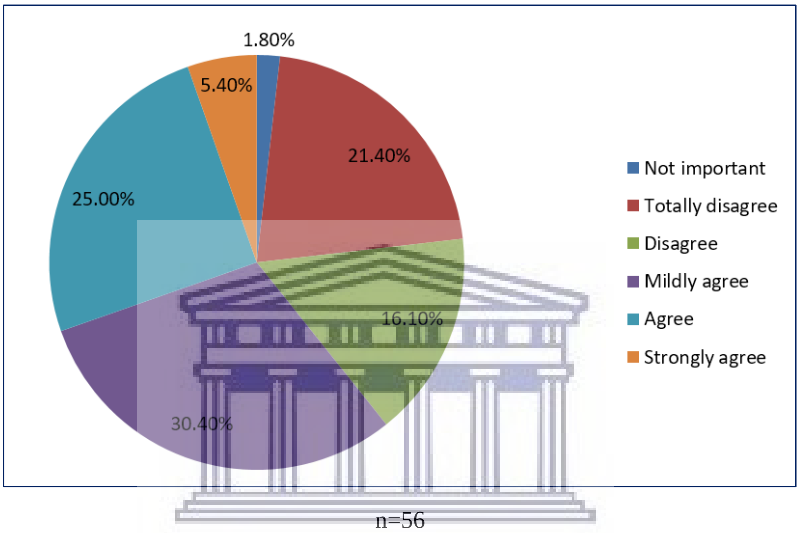

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Figure 5.10: Respondents' attitudes towards death as the worst thing that can happen to a patient

5.6.3 Talking to a Dying Patient About Impending Death

Figure 5.11 shows a varied response—32.1% mildly agreeing, 12.5% totally disagreeing, 32.1% disagreeing, 14.3% agreeing and 7.1% strongly agreeing, 1.8% reflected to be uncomfortable talking about impending death as not important. According to Denner (1999:434), some Professional Nurses find it difficult to talk about death with patients who are dying.

5.6.4 Continuation of Caring Attitude for the Patient's Family Throughout the Period of Grief and Bereavement

Figure 5.12 shows that the majority (55.4%) of the respondents totally disagreed, 32.1% disagree, 7.1% mildly agreed whilst 3.6% agreed that continuation of caring for the patient's family should persist throughout the period of grief and bereavement. Field & Cassel (1997:74) were of the view that continuation of caring for the patient’s family should be treated sensitively and the emotional needs of continuation of caring should be of a supportive nature.

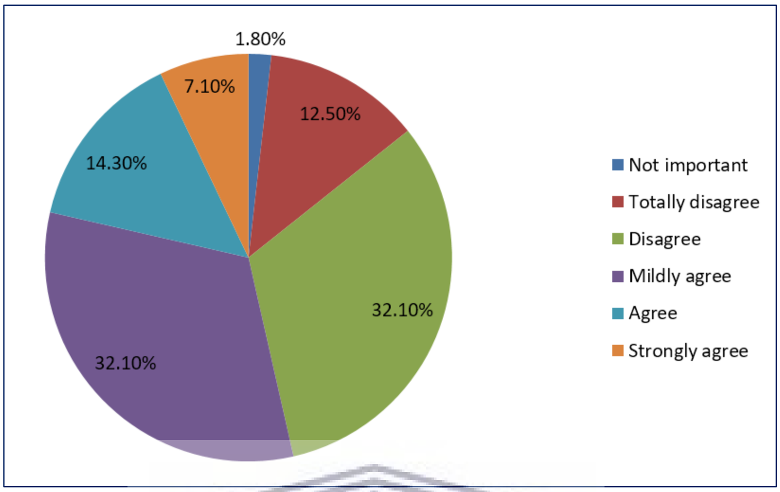

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Figure 5.11: Respondents’ attitudes towards talking to a dying patient about impending death

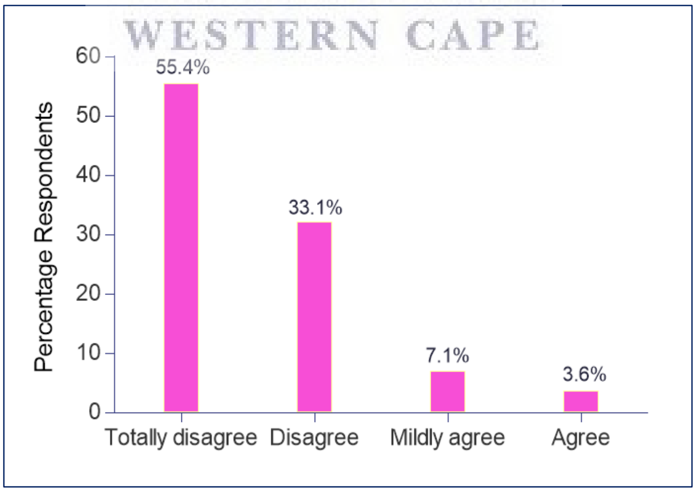

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Figure 5.12: Respondents’ attitudes towards continuation of caring attitude for the patient’s family

5.6.5 Would Not Want to be Assigned to Care for a Dying Patient

Figure 5.13 shows that the response categories varied, 1.8% not important, 7.1% strongly agreed, 28.6% mildly agreed, 25% strongly agreed, there was balanced response in totally disagreeing and disagreeing equal both respondents was 14.3% response. Notwithstanding, Sinclair & Hamil (2007:350) emphasised that nurses experience the care of the patient who is dying as physically and emotionally demanding the majority of the respondents strongly agreed they did not have a problem with being assigned to the care of a patient who is dying.

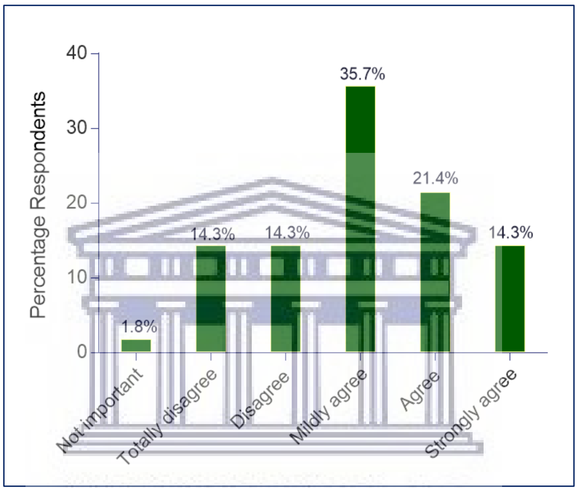

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Figure 5.13: Respondents' attitudes towards being assigned to care for a dying patient

5.6.6 Talking About Death to a Dying Patient

Figure 5.14 revealed that of the respondents, 14.3% strongly agreed, 21.4% agreed and 35.7% mildly agreed in contrast to the 14.3% who disagreed and 14.3% who totally disagreed that the Professional Emergency and Oncology Nurse should not be the one to talk about death to the patient who is dying. A lack of experience may contribute towards the respondents who strongly agreed 14.3% and agreed 21.4% having negative feelings when talking about death with the dying person. It is important to provide a reflective narrative environment in which Professional Nurses can express their personal feelings about speaking to a terminally ill cancer patient about death and dying (Payne, 2006). Costello (2006:594) emphasised the importance of the patients who are dying to verbalise their feelings that were synonymous with a good death in honest and open exchange of the physical needs of the dying person being met.

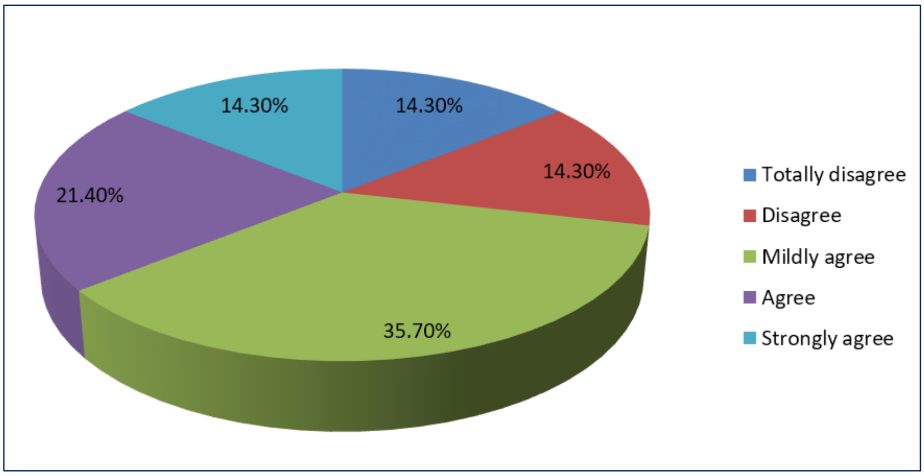

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Figure 5.14: Respondents' attitudes towards talking about death to a dying patient

5.6.7 Length of Time Required to Give Nursing Care to a Dying Patient Would Be Frustrating

Figure 5.15 indicates that 1.8% of the respondents regarded that the *Length of Time Required to Give Nursing Care to a Dying Patient Would Be Frustrating* as not important, 12.5% disagreed, 33.9% s mildly agreed, 25% agreed whereas 26.8% strongly agreed that the length of time required to give nursing care to a dying person would be frustrating them. According to Peteet et al. (1989:979), Professional Nurses regard their relationship with their dying patients as unique because of the increasing demands of the patient happening over a long period.

5.6.8 Caring for Patients Who Have Given Up Hope of Getting Better

Figure 5.16 reflects varied results of the respondents: 23.2% mildly agreed, 26.8% of the respondents agreed in contrast to 8.9% who totally disagreed and 14.3% who disagreed that they would be upset if the person that they are caring for should give up hope of getting better, whereas 1.8% said that it is not important. The fact that the majority of the respondents agreed and mildly agreed to becoming upset if the person they were caring for had given up hope of getting better is an important characteristic of Kubler-Ross's (1969:268) emphasis that an important characteristic of a meaningful relationship between the nurse and the patient is when the nurse is ready and able to share a few of the patients concerns.

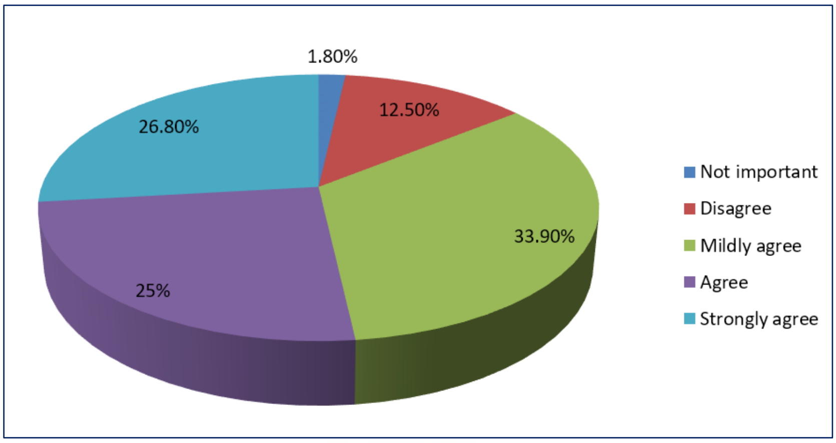

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Figure 5.15: Respondents' attitudes towards length of time required to care for a dying person

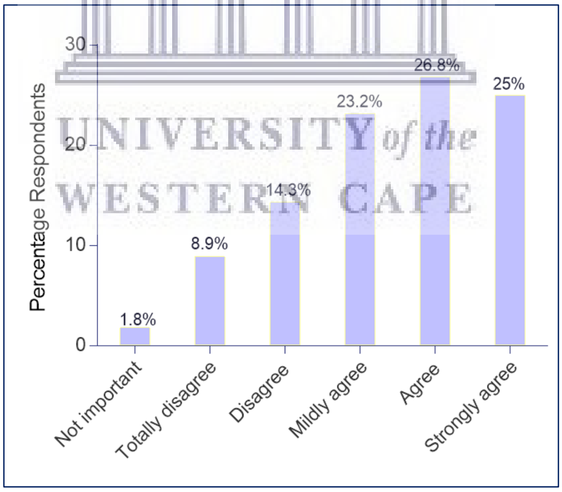

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Figure 5.16: Respondents' attitudes towards caring for patients who have given up hope of getting better

5.6.9 Difficult to Form a Close Relationship with the Family of a Dying Person

Figure 5.17 reveals that 21.4% of the participants strongly agreed, 28.6% agreed, 23.2% mildly agreed, 16.1% disagreed and 8.9% totally disagreed. Interestingly, 1.8% of the respondents considered it not important to form a close relationship with the family of a person that is dying. Peteet (1989:978) experienced that Oncology Nurses had become more emotionally involved with patients who are dying because of their direct involvement with life and death issues as compared to the Professional Emergency Nurse.

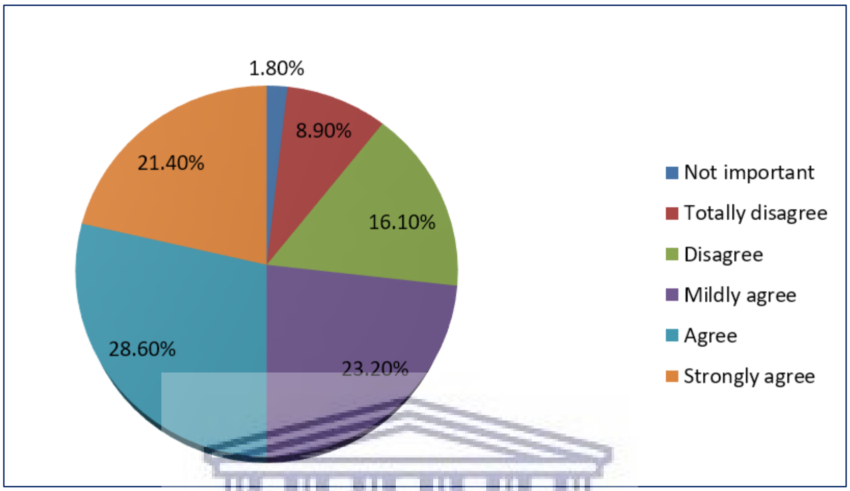

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Figure 5.17: Respondents' attitudes towards forming a close relationship with the family of a dying patient

5.6.10 Changing the Subject to Something More Cheerful When the Patient Asks "Nurse Am I Dying?"

Figure 5.18 reflects varied responses from 19.6% strongly agreeing, 17.9% agreeing to 32.1% mildly agreeing and 12.5% disagreeing as to 17.9% totally disagreeing, with equal number of respondents mildly agreeing and totally disagreeing that they would feel like running away, should the person actually die. As highlighted by Albett & Jones (2006:736), Professional Nurses working in Palliative Care wish to spend more time at the bedside of the patient who is dying and wish to be present when the patient dies.

5.6.11 The Family Should be Involved in the Physical Care of the Dying Patient

Figure 5.19 reveals that 58.9% totally disagree, 28.6% disagree, 32.1% mildly agree, 1.8% agree and 3.6% strongly agree that the family should be involved in the physical care of the dying person.

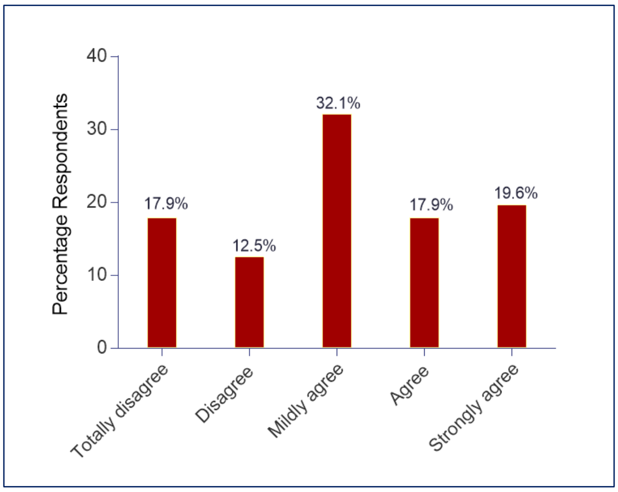

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Figure 5.18: Respondents' attitudes towards changing the subject when the patient asks, "Nurse, am I dying?"

The results illustrate that the majority of the Emergency and Oncology Nurses experience the family should not be involved in the physical care of the dying person. Costello (2006:594) emphasised the importance of the patients who are dying to verbalise their feelings that was synonymous with a good death in honest and open exchange of the physical needs of the dying person being met.

Nursing care must be open and sensitive towards the needs of the dying person, as supported by Field & Cassel (1997:74) who recommended that the nurse must be emotionally open and sensitive to the needs of the dying patient and their family on a continuous basis and the accompaniment of the patient as they travel the journey of life ending to include the family. A relationship of the patient with the family forms an integral part of the physical care of the patient.

The results of totally disagreeing 58.9% may reflect that external factors could contribute towards not allowing the family to be involved in the physical care of the dying patient. Barriers to allowing the family's involvement could be lack of time, personal, cultural or institutional factors, and professional educational needs. By addressing these, we may make an important contribution to the improvement of patient care towards the EOL (Bock, 2006:35).

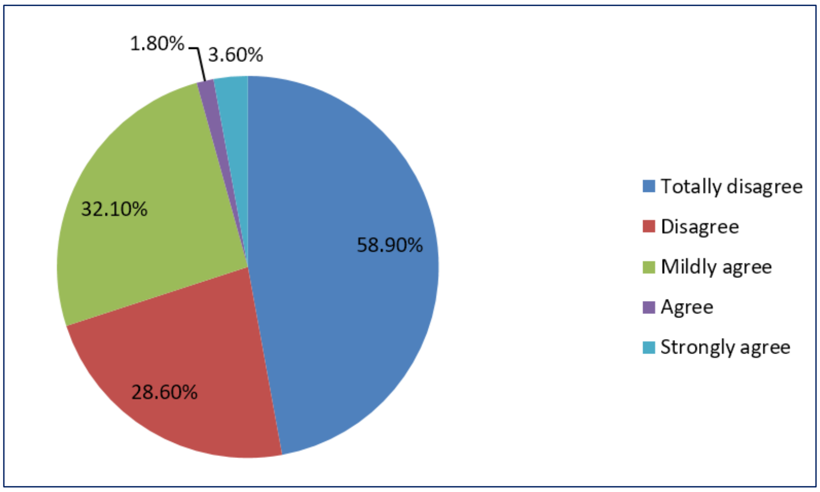

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Figure 5.19: Respondents' attitudes towards family involvement in the physical care of the dying patient

5.6.12 Hopes the Patient I Am Caring for Dies When I Am Not Present

Figure 5.20 shows the responses of the categories not important 1.8%, totally disagree 12.5%, disagree 26.8%, mildly agree 19.6%, agree 16.1% and strongly agree, while 23.2% hope the person they care for dies when they are not on duty. Albett & Jones (2007:736) experienced that Professional Nurses who cared for patients at the end of their life viewed it as a privilege. In addition, they reiterated that Professional Nurses do make a difference when they spend time with the patients at near EOL.

5.6.13 Afraid of Becoming Friends with a Dying Patient

Figure 5.21 indicates responses as follows; 17.9% disagree, 23.2% mildly disagree, 30.4% agree and 28.6% strongly agree in being afraid of becoming friends with a dying patient. Rittman et al. (1997:118) observed that nurses had identified the development of a special connection with the patient as vital in caring for dying patients.

5.6.14 The Family Need Emotional Support to Accept the Behavioural Changes of the Dying Patient

Figure 5.22 reveals findings in the following categories: 64.3% totally disagree, 26.8% disagree, 3.5% mildly agree and 5.4% strongly agree in offering the family emotional support to accept the behavioural changes of the dying person. Field & Cassel's (1997:74) stated that nurses who care for the patients who are dying in offering them emotional support should be sensitive to the emotional needs of the family of the patient during the end of the dying person's life, i.e., at the EOL phase and to continue after the patient has passed away.

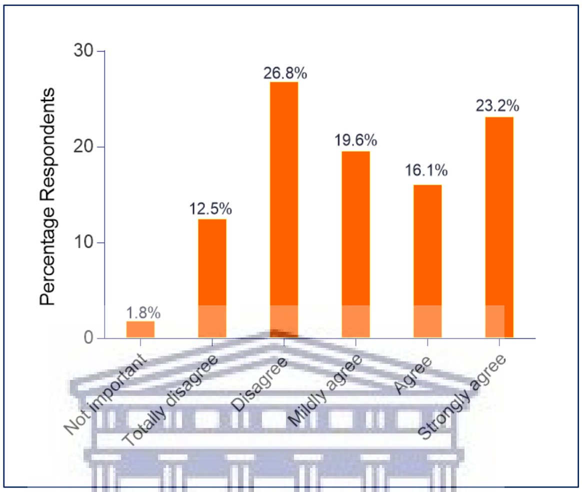

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Figure 5.20: Respondents' attitudes towards "Hopes the patient I am caring for dies when I am not present."

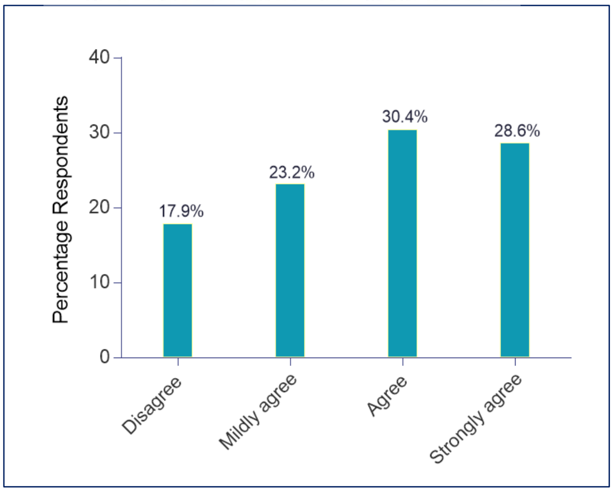

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Figure 5.21: Respondents' attitudes towards "Afraid of becoming friends with a dying patient."

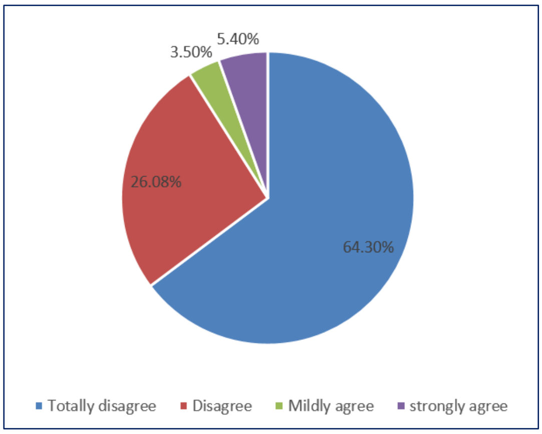

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Figure 5.22: Respondents' attitudes towards "Families need emotional support to accept the behavioural changes of the dying patient."

5.6.15 The Family Should Be Concerned About Helping Their Dying Member Make the Best of His/her Remaining Life

Figure 5.23 shows the following findings in the categories: 1.8% not important, 67.9% totally disagree, 21.4% agree, 7.1% mildly agree and 1.8% strongly agree that the family should be concerned about helping their dying member make the best of his/her life. Rittman et al. (1997:118) stated that nurses should be encouraged to support the family to be with the patient while s/he is dying. They further emphasised the presence of loved ones had contributed towards the state of peace towards dying.

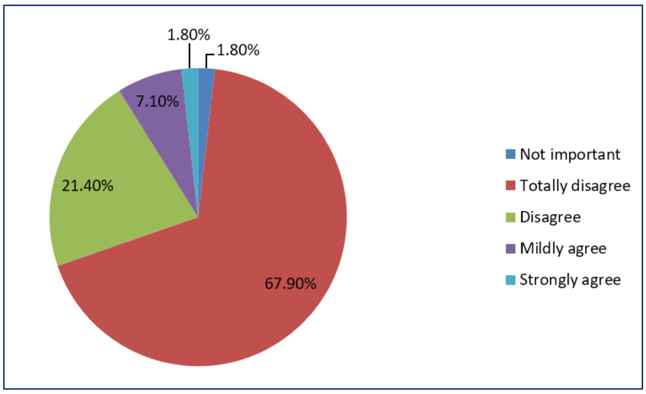

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Figure 5.23: Respondents' attitudes towards "Families should be concerned about helping their dying member make the best of his/her remaining life."

5.6.16 The Dying Person Should Not Be Allowed to Make Decisions About His/her Physical Care

Figure 5.24 shows that in the specified categories 12.5% of the respondents totally disagreed, 19.6% disagreed, 23.2% mildly agreed, 17.9% agreed and 26.8% strongly agreed that the dying person should not be allowed to make their own decisions regarding his/her physical care. Allen (2009:19) stated the achievement of a sense of control by the patient is characteristic of EOL care as supported in the recommendations of the Palliative Care Overview (2012).

5.6.17 The Family Should Maintain As Normal An Environment As Possible for Their Dying Member

Figure 5.25 shows that of the respondents, 44.6% totally disagreed, 33.9% disagreed, 16.1% mildly agree agreed, 3.6% agreed and 1.8% strongly agreed that families should maintain a normal environment for their dying member. The Palliative Care Overview (2012) recommended that the dying patient should be approached as part of the family, hence acknowledging the importance of maintaining an environment of function as normally as possible for their dying family member.

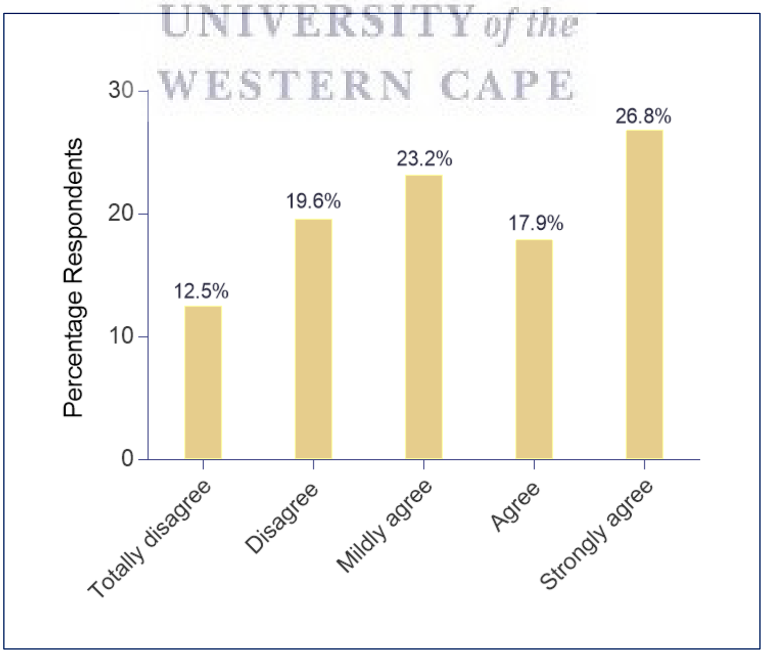

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Figure 5.24: Respondents' attitudes towards "The dying person should not be allowed to make decisions about his/her physical care."

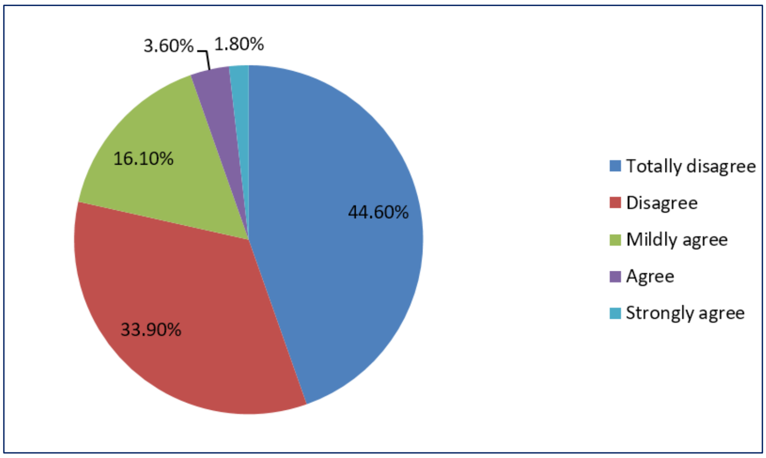

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Figure 5.25: Respondents' attitudes towards "Families should maintain as normal an environment as possible for their dying member."

5.6.18 Nursing Care Should Extend to the Family of the Dying Person

Figure 5.26 reveals the results in the following categories of responses: 51.8% totally disagreed, 28.6% disagreed, 10.7% mildly agreed, 7.1% agreed and 1.8% strongly agreed that nursing care should be extended to the family of the dying person. Rittman et al. (1997:116) recommended that the nurse be open and honest towards the emotional needs of the patient who is dying and to extend the care to the family on an as needed by the patient and the family basis.

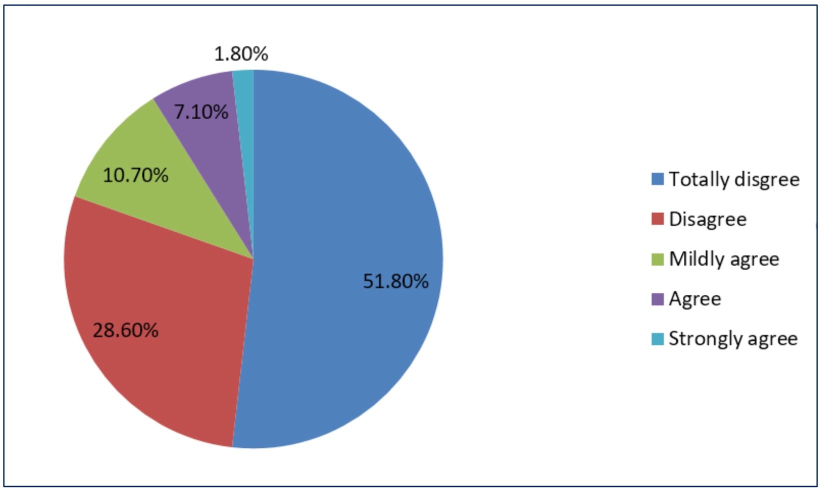

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Figure 5.26: Respondents' attitudes towards "Nursing care should extend to the family of the dying patient."

5.6.19 Nurses Should Permit Dying Patients to Have Flexible Visiting Schedules

Figure 5.27 shows that of the respondents, 62.9% totally disagreed, 30.4% disagreed, 5.4% mildly agreed and 1.8% strongly agreed to have flexible visiting schedules. Rittman et al. (1997:115) emphasised that nurses should request the family and significant others to be present in the caring for the dying patient, allowing open flexible visiting times, which is in contrast to the 62.9% of respondents in this study who totally disagreed that visiting times should be flexible.

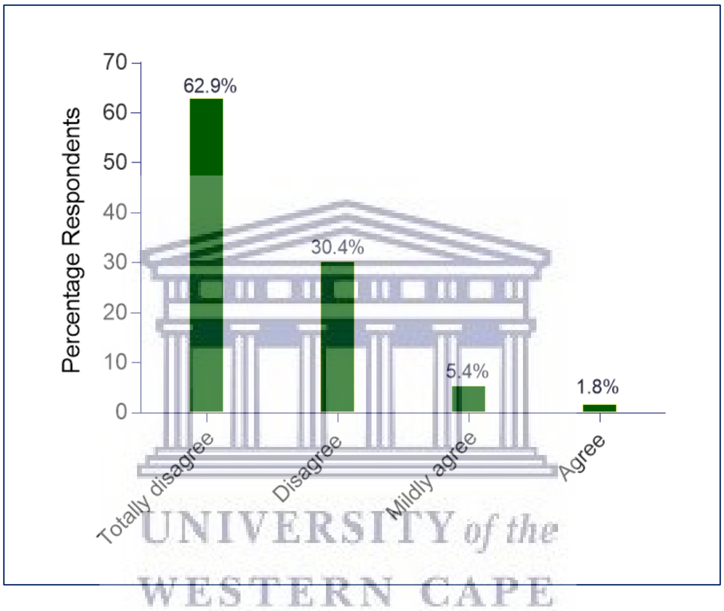

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Figure 5.27: Respondents' attitudes towards "Nurses should permit dying patients to have flexible visiting schedules."

5.6.20 The Dying Patient and His/her Family Should Be In Charge As Decision Makers

Figure 5.28 shows that 33.9% of the respondents totally disagreed, 39.3% disagreed, 14.3% mildly agreed, 8.9% agreed and 3.6% strongly agreed that the patient's family should be in charge of the decision-making. Allen (2009:19) stated that one of the goals of EOL is the achievement of a sense of control by both the patient and the family being involved.

5.6.21 Addiction to Pain-Relieving Medication Should Not Be a Nursing Concern When Administering

Figure 5.29 shows that of the respondents, 1.8% indicated that it was not important, 26.8% totally disagreed, 21.4% disagreed, 25.0% mildly agreed, 19.6% agreed and 5.4% strongly agreed that addiction in pain-relieving medication should not be a nursing concern when administering such. One of the fundamental tenets of palliative care as quality EOL is adequate pain control and the effective management of symptoms caring for the patient who is dying (Allen, 2009:18).

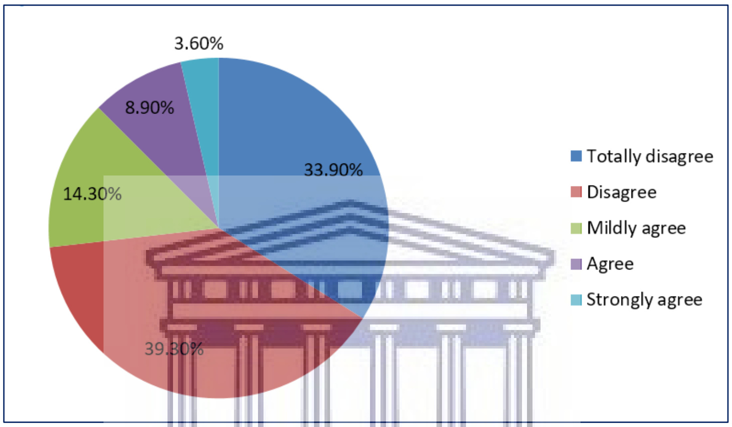

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Figure 5.28: Respondents' attitudes towards "The dying patient and his/her family should be in charge as decision makers."

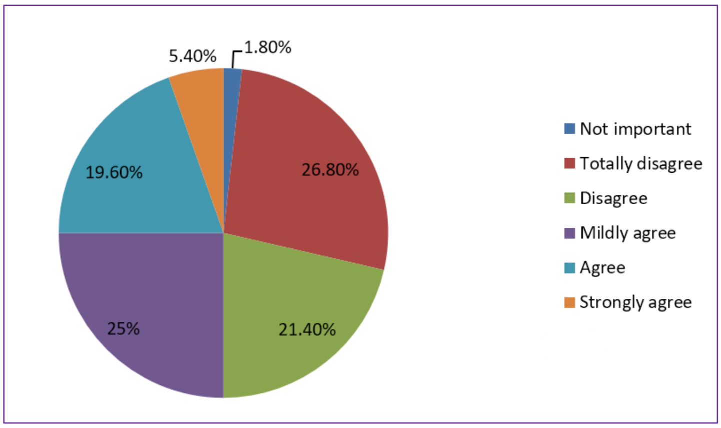

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Figure 5.29: Respondents' attitudes towards "Addiction to pain-relieving medication should not be a nursing concern when administering."

5.6.22 I Would Be Uncomfortable If I Entered the Room of a Terminally Ill Patient found Him/her Dying

Figure 5.30 shows that 17.9% totally disagreed, 21.4% disagreed, 21.4% mildly agreed, 19.6% agreed and 19.6% of respondents strongly agreed that they would be uncomfortable entering the room of a terminally ill person and found him/her dying. Albett & Jones (2006:736) emphasised that the Professional Nurses working in palliative care should encourage the family or loved ones to have special times at the bedside of the patient and to be present when the patient dies.

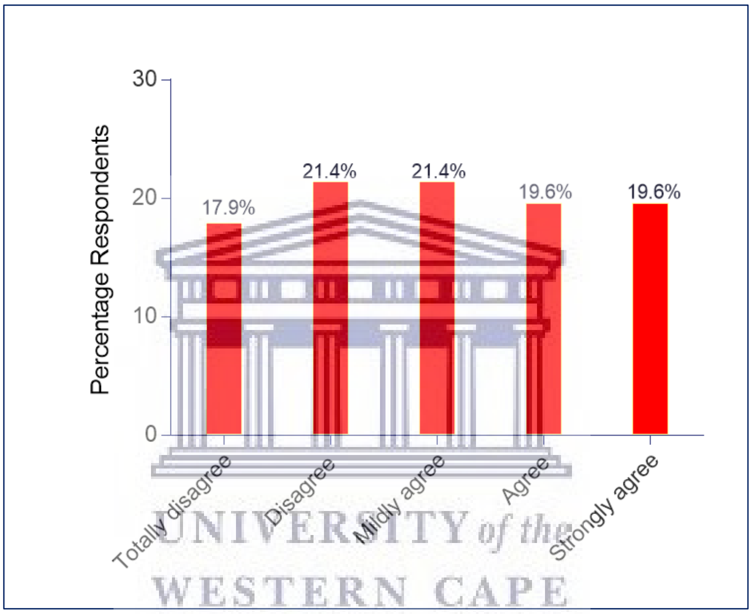

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Figure 5.30: Respondents' attitudes towards "I would be uncomfortable if I entered the room of a terminally ill patient and found him/her dying."

5.6.23 Dying People Should Be Given Honest Answers About Their Condition

Figure 5.31 shows that of the respondents, 53.6% totally disagreed, 33.9% disagreed, 8.9% mildly agreed, 1.8% agreed and 1.8% strongly agreed that dying people should be provided with honest answers about their condition. Professional nurses caring for cancer patients at the EOL have a moral and professional obligation to advocate the patients' goals of care and answering of concerns while following ethical principles (Payne, 2009).

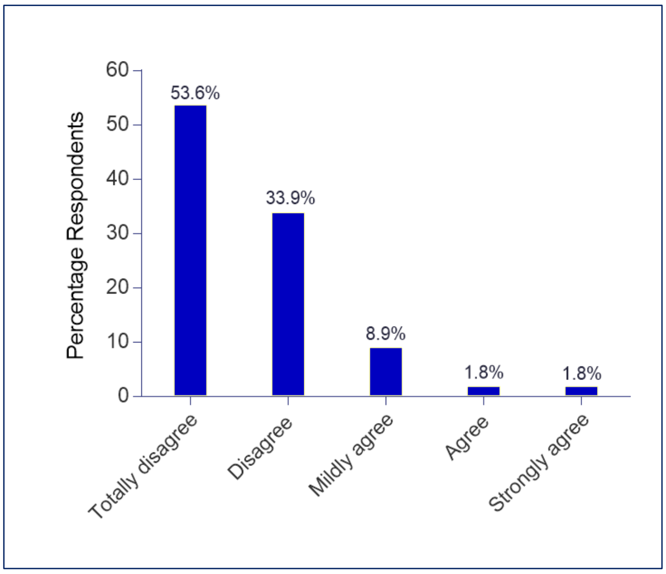

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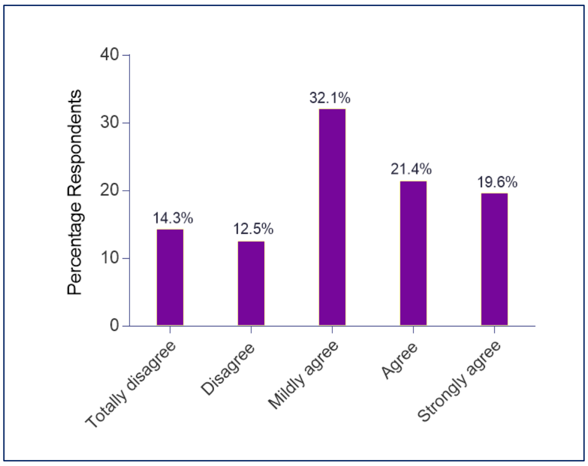
Figure 5.31: Respondents' attitudes towards "Dying people should be given honest answers about their condition."

5.6.24 Educating the Family About Death and Dying Is Not a Nursing Responsibility

Figure 5.32 reveals of the respondents, 14.3% totally disagreed, 12.5% disagreed, 32.1% mildly agreed, 21.4% agreed and 19.6% strongly agreed that education of the family about death and dying is not a nursing responsibility. The results are congruent with Costello's (2005:598) research findings in that nurses should prepare both the patients and their families for death by alleviating any concerns they might present with regarding EOL matters.

5.6.25 Summary of Emergency and Oncology Nurses' Attitudes Towards Caring for the Dying

Section C, i.e., Objective 1 was to investigate the attitude of the Professional Emergency and Oncology Nurse regarding palliative care nursing practices/procedures. The Frommelt Tool was used as a guide to investigate the attitudes of the Emergency and Oncology Nurses. Caring for patients nearing the EOL often enables nurses to bear witness to the complicated and difficult decisions that patients and families must make surrounding sensitive issues.



n=56

Figure 5.32: Respondents' attitudes towards "Educating the family about death and dying is not a nursing responsibility."

It is known that nurses have their own morals and beliefs; however, sometimes their attitudes do not correspond with the patients' values, beliefs and wishes. The Professional Nurse should be able to focus on helping the patient, and weigh the benefits and burdens of the intervention rather than focus on the intervention itself (Litcher, 1991). Section D will address Objective 2 of the study by identifying the palliative nursing care practices and protocols that are nurses are familiar with and use for the Oncology Patient.

5.7 SECTION D: PRACTICE OF THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

Section D is based upon the practice of the Professional Emergency and Oncology Nurse. The SA Hospice Association Guidelines were used to measure the practices of the Emergency and Oncology Professional Nurse.

- OBJECTIVE 1

To investigate the knowledge, attitudes and practices of the Emergency and Oncology Nurses regarding palliative care nursing practices/procedures for Oncology Patients in three of the Western Cape Provincial Hospitals.

5.7.1 Nurses' Practices Towards Caring for the Dying

5.7.1.1 Section 56(A) of the Nursing Act Allowing Palliative Care Nurses to Dispense Drugs

Figure 5.33 shows that 28.6% of the respondents never used Section 56(A) of the Nursing Act, 10.7% seldom used it, 30.4% sometimes used it, 16.1% use it most of the time while 14.3% used it all the time. Professional Nurses working in Oncology have an important role to play in this regard because within Section 56(A) is the opportunity to be central in functioning being able to diagnose and prescribe medication according to the needs of the institution and to prescribe medication for the Oncology Patient (Abelson, 2010).

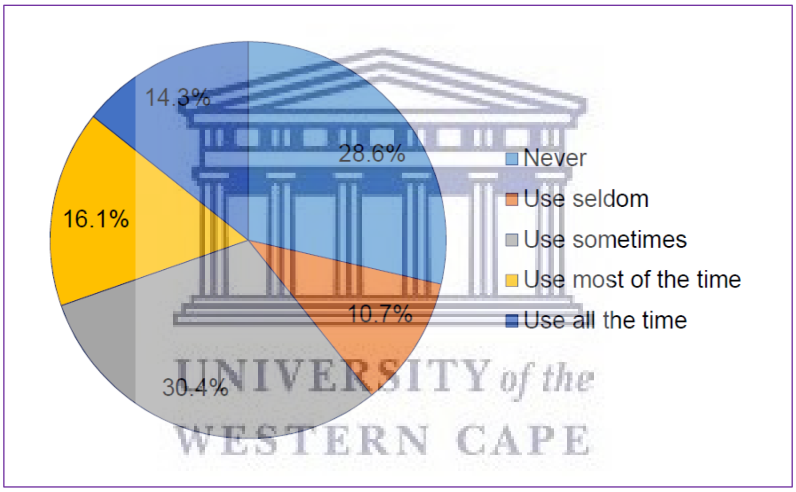


Figure 5.33: Respondents' use of Section 56(A) of the Nursing Act

5.7.1.2 Prognosticating Disease and Death

Figure 5.34 reflects that 23.2% of the respondents have never prognosticated disease and death, 21.4% used seldom, 17.9% sometimes did use prognoses and death and 26.8% used most of the time as to only 10.7% who are involved in the prognosticating of disease and death. Research has indicated that if there are shortcomings in in prognosis-related communication with patients who have advanced cancer this may have negative outcomes for patients and Professional

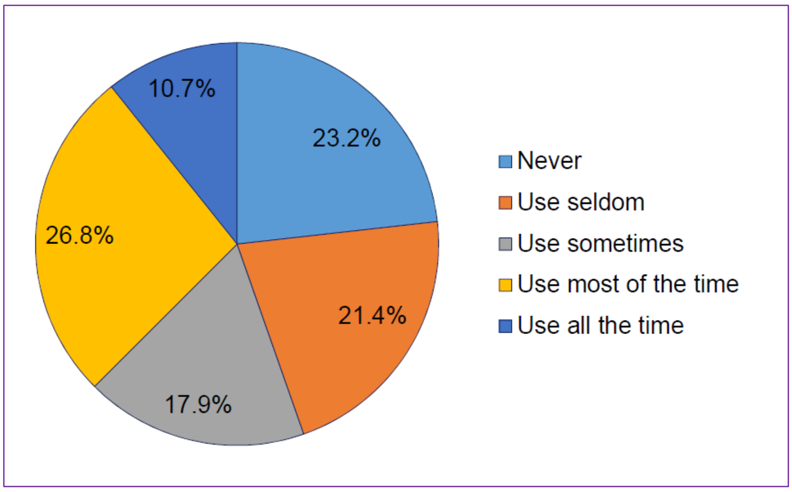


Figure 5.34: Prognosticating disease and death

5.7.1.3 Hospice Palliative Care Association Guidelines

Figure 5.35 shows that 28.6% of the respondents had never use the Hospice Palliative Care Association Clinical Guidelines, 11.1% used seldom, 22.2% used sometimes, 15.9% used most of the time and 22.2% used all of the time.

5.7.1.4 Management of Pain

Figure 5.36 indicates that 1.8% of the respondents had never used pain management, 8.9% used seldom, 14.3% used sometimes, 33.9% used most of the time and 41.1% used it all the time. The literature has supported that Professional Nurses have knowledge in the field of management of pain in the cancer patient as reflected in the respondents that 41.1% used pain management all the time. Professional Nurses working with cancer patients serve as advocates toward the empowering of patients to engage in self-management of pain, in supporting the patient and their family at the most vulnerable times (Vallerand, Musto & Polmano, 2011:250).

5.7.1.5 Management of Respiratory Symptoms

Figure 5.37 shows that 3.6% of the respondents had never managed respiratory symptoms of a patient, 12.5% seldom used, 25% used sometimes, 28.6% used most of the time and 30.4% used management of respiratory symptoms all the time.

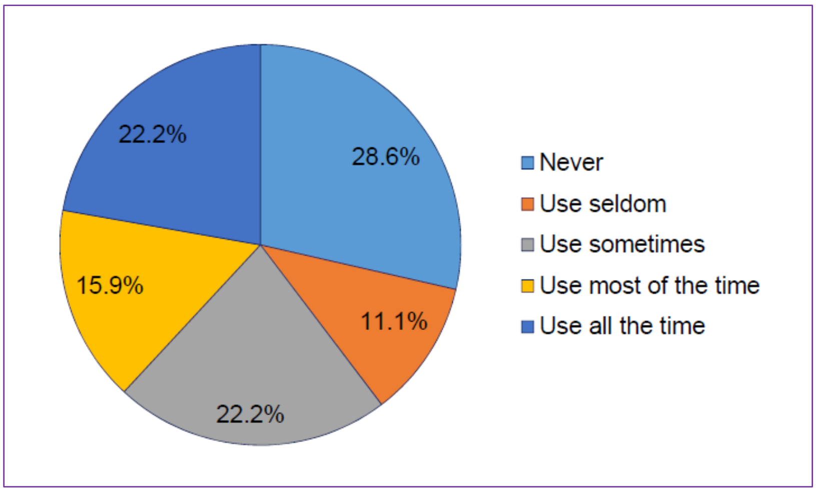


Figure 5.35: Hospice palliative care association guidelines

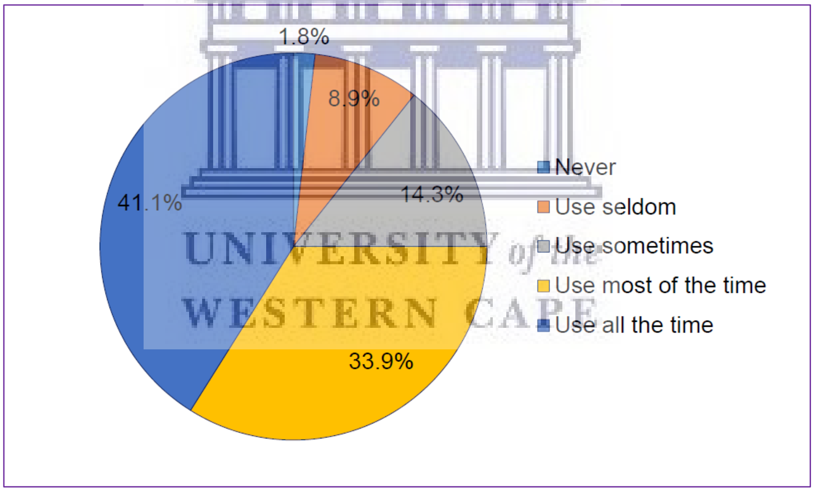


Figure 5.36: Management of pain

The majority of the respondents had managed respiratory symptoms in a cancer patient; these symptoms can result in feelings of impaired physical and social functioning and influencing QOL. Specific interventions are needed to manage dyspnoea in improving breathing efficiency. Yates et al. (2013:2072) reported management of respiratory symptoms to be effective as pursed lip breathing, diaphragmatic and paced breathing, positioning and psychological interventions to reduce anxiety and distress.

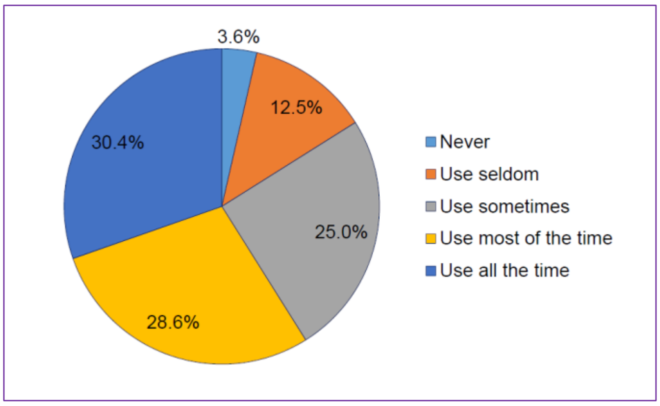


Figure 5.37: Management of respiratory symptoms

5.7.1.6 Management of Gastrointestinal Symptoms

Figure 5.38 reflects that 3.8% of the respondents never managed gastrointestinal symptoms, 13.5% used seldom, 21.2% used sometimes, 30.8% used most of the time and 30.8% used all of the time. The results indicate that between 3.6% and 12.5% never and seldom managed gastrointestinal symptoms, for various reasons—literature has reflected the care pathway of gastrointestinal symptoms is completed and normally recommended to Specialist Nurses (Vilkund,Wengstrom & Lagergren, 2006). However, it is important that all Professional Nurses working in Emergency and Oncology be experienced in managing gastrointestinal symptoms because the patient presents with fatigue that is an important problem and regarded by patients as more important than either pain or nausea or vomiting (Stone, Richardson, Ream, Smith, Kerr & Kearney, 2000:971).

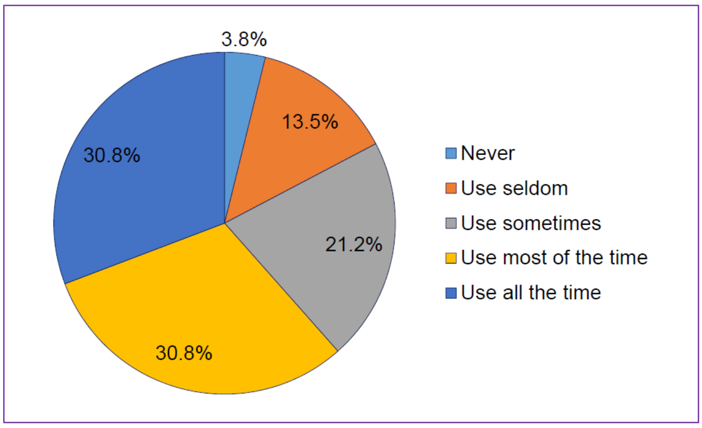


Figure 5.38: Management of gastrointestinal symptoms

5.7.1.7 Management of Neurological Psychiatric Symptoms

Figure 5.39 shows that 17.9% of the respondents had never managed neurological psychiatric symptoms, 21.4% used seldom, 19.6% used sometimes, 23.2% use most of the time and 17.9% used the management of neurological symptoms all the time. The respondents' results illustrate that only 17.9% manage neurological symptoms all the time. It is important that patients have the ability to tolerate the consequences of their disease and they will thus need the support of the available social structure as family to provide emotional strength and social support (Holland & Tross, 1985). The important symptoms for the Professional Nurse to manage are anxiety, depression and delirium. Neurologic complications are frequent—the most common being dementia and encephalopathy that are often poorly understood and managed.

5.7.1.8 Management of Constitutional Symptoms of Anorexia, Asthenia, Cachexia, Fever and Sweating

Figure 5.40 demonstrates that 26.8% of the respondents had never managed, 12.5% used seldom, 17.9% used sometimes, 25% used most of the time and 17.9% used all of the time. It is vital for the Professional Nurse to know how to manage the constitutional symptoms, it has been reported by (Hurtado & Krakauer, 1999) that more than 50% of patients with cancer often are significantly compromised, both physically and due to loss of QOL, fatigue fever or sweats. These symptoms can include opportunistic infections and which can further lead to malignancy and medication modifications, if not managed correctly.

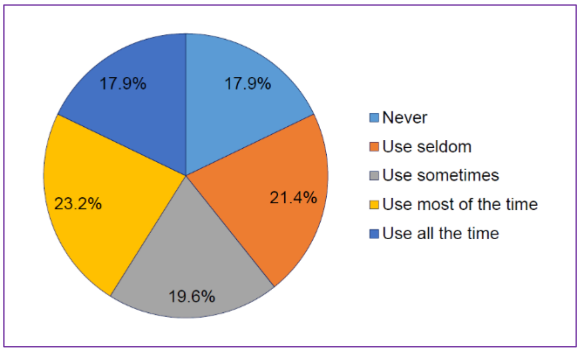


Figure 5.39: Management of neurological psychiatric symptoms

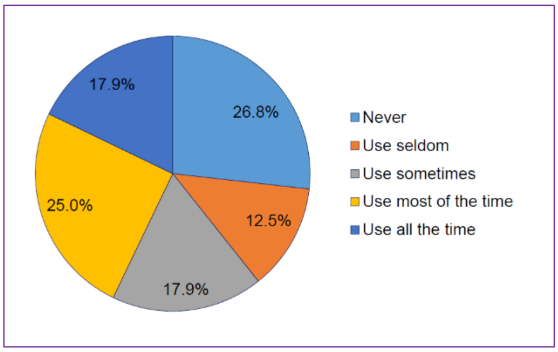


Figure 5.40: Management of constitutional symptoms of anorexia, asthenia, cachexia, fever and sweating

5.7.1.9 Management of Infective Symptoms

Figure 5.41 reflects that 25% of the respondents had never managed infective symptoms, 5.4% used seldom, 16.1% used sometimes, 30.4% used most of the time and 23.2% used all the time the management of infective symptoms. The results indicate that the majority had managed infective symptoms. The results reflect that 25%, never managed infective symptoms—this is an important principle in palliative care because in managing infective symptoms, supportive care is started as smooth quality communication for treatment is taking into account the symptoms experienced by the patient and the rehabilitation needed (Park, Chung & Shin, 2012:4953). An integrated pain and infective symptoms management is vital, including psychological support and education for the patient and his/her family.

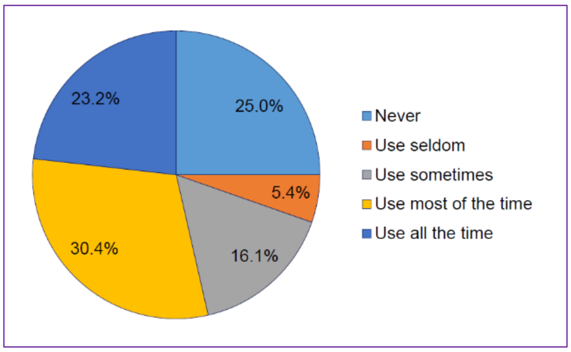


Figure 5.41: Management of infective symptoms

5.7.1.10 Management of Urinary Symptoms

Figure 5.42 shows that 23.2% of the respondents had never managed urinary symptoms, 1.8% used seldom, and 17.9% used some times, 28.6% used most of the time and 28.6% used all of the time. The results for the management of urinary symptoms were similar for used most of the time and used all of the time, i.e., 28.6%. The importance of managing urinary symptoms cannot be overemphasised. Research supports that it is vital to manage the Cancer Patient with urinary symptom as other symptoms, holistic symptom control, psychological support, urinary support and management as EOL care and continence care should be based on the patient’s wishes and preference. Professional nursing care should be upheld and maintained at all times in comforting the patient, upholding their dignity and relieving the symptoms (Harris, 2009:105).

In addition, Harris (2009:105) accentuated that the management of urinary symptoms must be a collaborative approach between continence and the palliative care professionals to develop and equip the patient and their family gently towards EOL care.

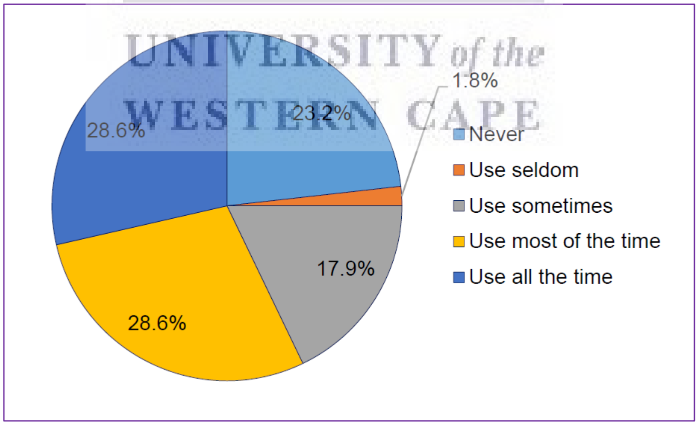


Figure 5.42: Management of urinary symptoms

5.7.1.11 Management of Pressure Care and Wound Care

Figure 5.43 reflects the results of the management of pressure and wound care. Of the respondents, 21.4% had never experienced pressure and wound care, 1.8% used seldom, 17.9% used sometimes, 23.2% used most of the time. The management of pressure and wound care is a form of palliative care as it supports the health care needs of the terminally ill cancer patient by focusing on alleviating the symptoms. Furthermore, pressure care and wound care must not be experienced as separate nursing care as reflected by 21.4% of the respondents who had never experienced pressure and wound care.

The management of pressure and wound care can be healing and palliative in improving the quality of EOL care for the terminally ill cancer patient. Literature supports that the quality of managing pressure and wound care by Professional Nurses has to done with proper consideration of the patient’s wishes and best interests (Weissman, 2000).

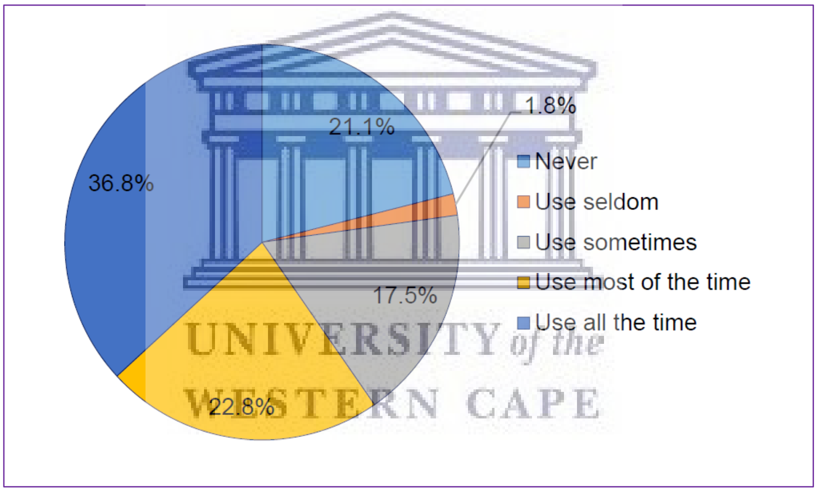


Figure 5.43: Management of pressure care and wound care

5.7.1.12 Management of Patients in the Terminal Phase

Figure 5.44 reflects that 25% of the respondents had never managed patients in the terminal phase, 10.7% used seldom, 10.7% used sometimes, 25% used most of the time and 28.6% used all the time. Evidence-based research reported feelings of emotional distress, anxiety coupled with a lack of preparation to provide care to patients at EOL and their families (Lewis, Reid, McLernon, Ingham & Traynor, 2016). However, several lines of evidence recommend that increased time spent with terminally ill cancer patients and their families can improve attitudes towards EOL care.

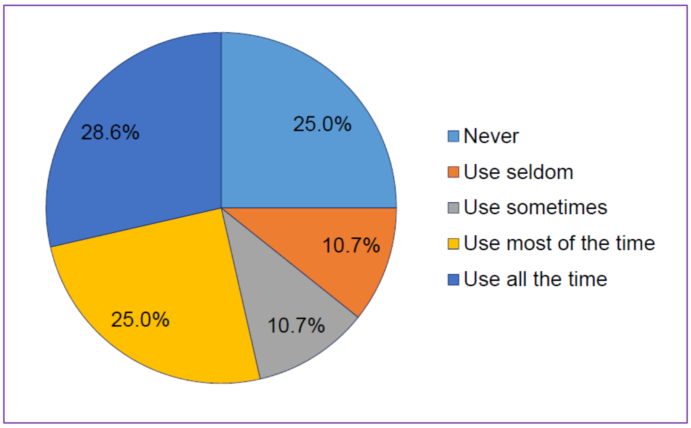


Figure 5.44: Management of patients in the terminal phase

5.7.1.13 Management of Palliative Care Emergencies

Figure 5.45 presents results of the management of palliative care as an emergency. Of the respondents, 7.1% had never managed palliative care as an emergency, 16.1% used seldom, 12.5% used sometimes, 26.8% used most of the time and 37.5% used all the time. The results show that 37.5% of the respondents had managed Palliative Care Emergencies. In Professional Nurses caring role and focussing on the management of the terminally ill cancer patient and critical body functions as in emergency care can be stressful for the Professional Nurse.

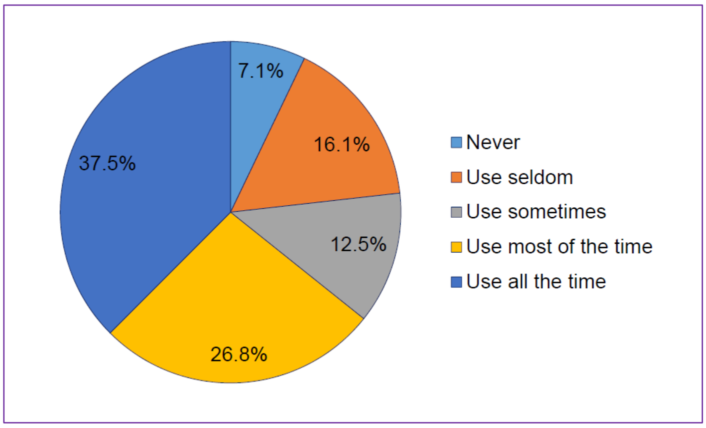


Figure 5.45: Management of palliative care emergencies

As supported in a study by Payne (2001), who identified “death and dying” as conflicting with their “accepting responsibility,” their environment and the organisational environment itself was a key stressor for the Professional Nurses, relating to team communication, inadequate resources and unrealistic expectations.

5.7.1.14 Management of Communication

Figure 5.46 shows that the management of communication results. Of the respondents, 3.6% had never managed communication, 19.6% used seldom, 12.5% used sometimes, 17.9% used most of the time and 46.4% used all of the time. Effective communication between Professional Nurses as health care providers, patients and their families is a very essential component within palliative care. The identification and management of symptoms—physical, spiritual and emotional—hinge on constant interaction (Holland & Chertkov, 2004).

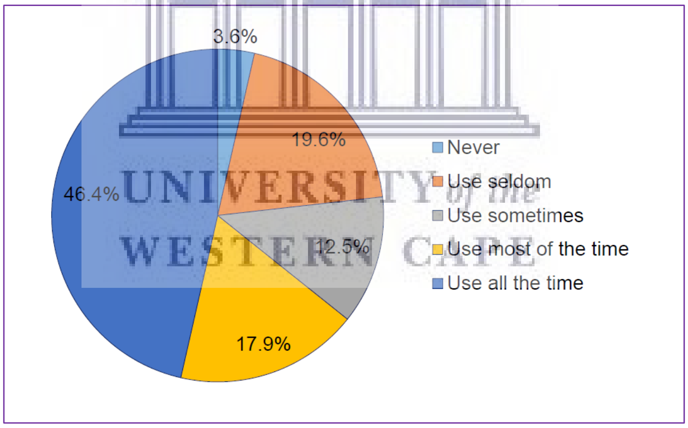


Figure 5.46: Management of communication

5.7.1.15 Breaking of Bad News and Building of Hope

Figure 5.47 reveals that 5.4% of the respondents had never experienced breaking of bad news and building of hope, 21.4% used seldom, and 14.3% used sometimes, 26.8% used most of the times and 32.1% used all of the time. Breaking of bad news and building of hope is one of the criteria of palliative care, because these are decisions that ensure that care and guidance on ethical moral values will enable the Professional Nurse to satisfy the criteria for a peaceful and dignified death (Bruera et al., 2004).

5.7.1.16 Performing a Psychosocial Assessment

Figure 5.48 shows that 8.9% of the respondents had never performed a psychosocial assessment, 19.6% used seldom, 25.0% used sometimes, and 16.1% used most of the time and 30.4% used all the time. It has been suggested that Professional Nurses believe they have the ability to perform a psychosocial assessment, but feel they lack adequate training or lack support to resolve the patient's spiritual distress and feel their viewpoints are only needed as routine assessment and duty-orientated tasks that prevent them from paying attention to the spiritual and emotional assessment needs of patients (Weissman, 2000).

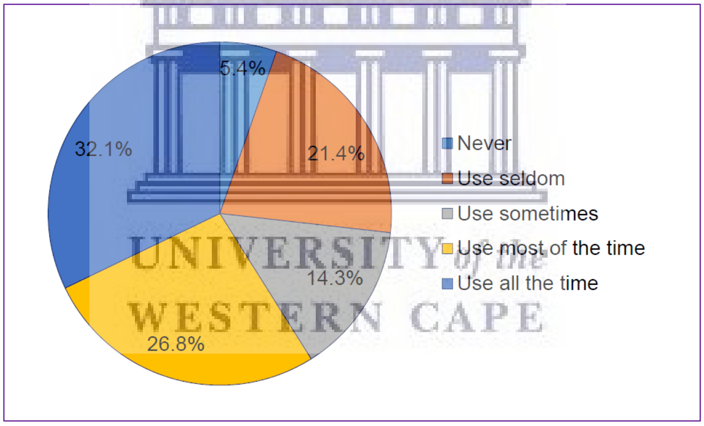


Figure 5.47: Breaking bad of news and building of hope

5.7.1.17 Management of Loss, Grief and Bereavement

Figure 5.49 indicates that 10.7% of the respondents had never managed of loss, grief and bereavement, 12.5% used the process seldom, 14.3% used sometimes, 30.4% used most of the time and 32.1% used all the time. Research has supported the view that loss grief and bereavement should be an interactive process, because if each component is dealt with individually, it could be effective in identifying the collective perceptions of the patients and their family's perceptions and fears. The professional experience of loss, bereavement and grief are central to effective and compassionate care of the dying patient and their family (Matzo, 2003:71).

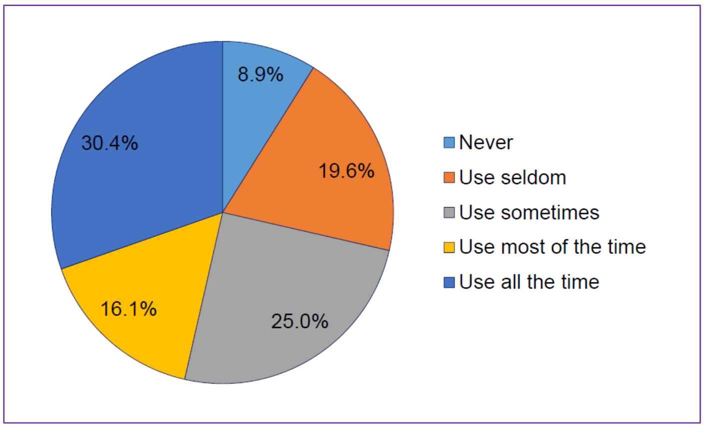


Figure 5.48: Performing a psychosocial assessment

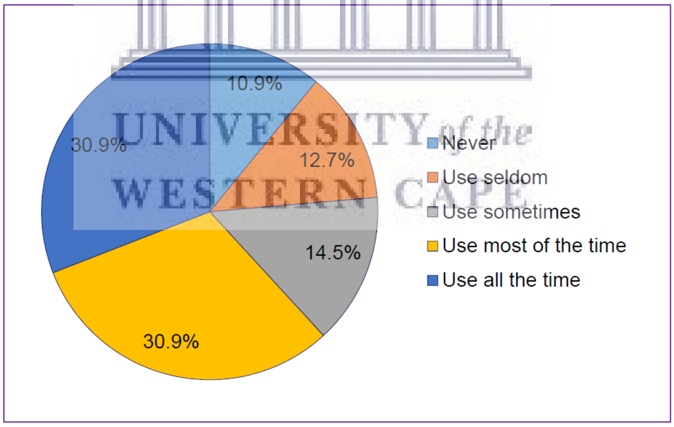


Figure 5.49: Loss, grief and bereavement

5.7.1.18 Culture and Spirituality Application in Palliative Care

Figure 5.50 reflects that 14.3% of the respondents had never considered the application of culture and spirituality in palliative care, 8.9% used seldom, 16.1% used sometimes, 28.6% used most of the time and 32.1% used all the time. Research has been limited in this area, however, there has to be an achievement in the way of the Professional Nurse caring for the patient, focusing on the presence of the patient and their family as they journey together. Literature has supported the physical way care was rendered, by listening and connecting as in palliative care engaging in reciprocal sharing, including the engagement of families in spiritual care and culture appears underutilised. Matzo (2003:71) supported this view by stating affirmative relationships support patients that, in turn, enable the patient to respond to their spiritual needs.

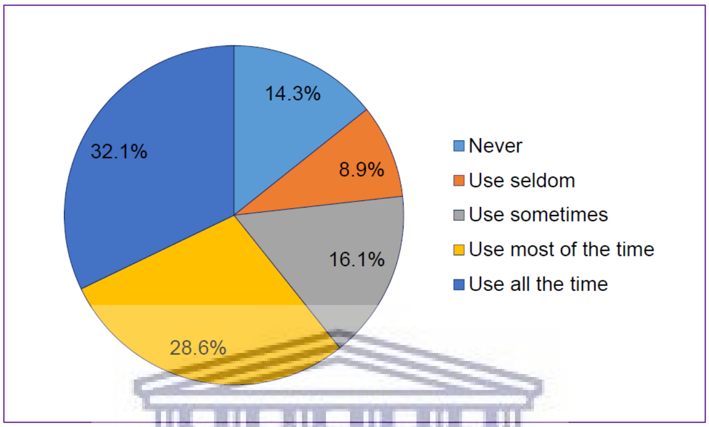


Figure 5.50: Culture and spirituality application in palliative care

5.7.1.19 Management of Psychosocial Emergencies—Suicide

Figure 5.51 shows that 14.3% of the respondents never managed psychosocial emergencies, for example, suicide, 12.5% managed seldom, 14.3% used sometimes, 21.4% used most of the time and 37.5% used all of the time. The researcher noted that more than half of the respondents (37.5%) had managed psychosocial emergencies. According to (Gutierrez, 2005:229) the deleterious effects will have an impact on the Professional Nurses well-being and can be later identified as a causative agent contributing to high nursing turn over burnout and nurses leaving the profession.

5.7.1.20 Management of Social Emergencies—Financial Issues

Figure 5.52 exhibits that 16.1% of the respondents had never managed social emergencies of a patient, 28.6% used seldom, 16.1% used sometimes, and 17.9% used most of the time and 21.4% used all of the time.

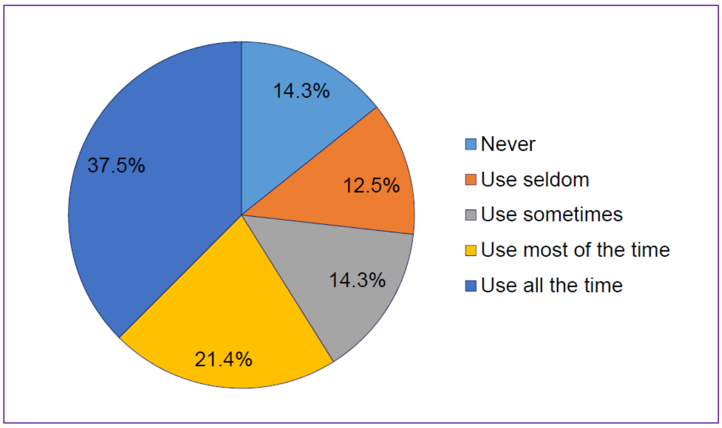


Figure 5.51: Management of psychosocial emergencies—suicide

There has been emerging evidence of Professional Nurses having heavy burdens as they deal with the continual loss of their patients.The loss in this case is each patient and his/her family have unique needs, including social, physical, psychological and spiritual, and should not be seen as a separate component. This is deserving of expert EOL care and it is this intensity of need that places the Professional Nurse at risk of professional compassion fatigue (Melvin, 2013).

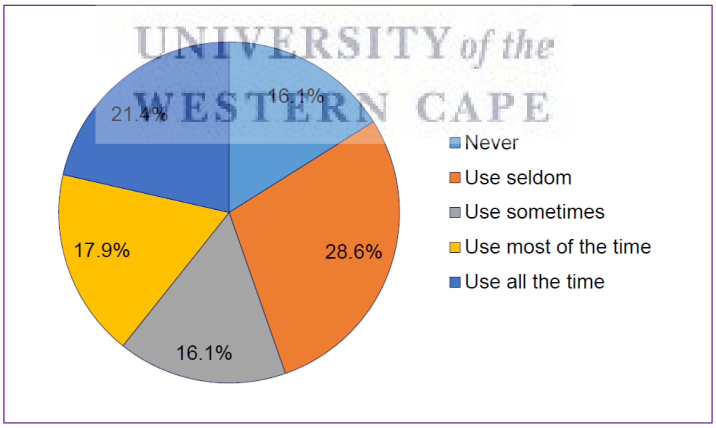


Figure 5.52: Management of psychosocial emergencies—financial issues

5.7.2 Context of Palliative Care Practices of the Emergency and Oncology Nurses

Section D addressed Objective 1, i.e., to investigate the practices of the Emergency and Oncology Nurses regarding palliative care practices and procedures for Oncology Patients in the hospital.

The experience in palliative care was measured in rating how familiar they were to palliative care practices. The results of Section D showed that the majority of nurses had little experience about palliative care. The findings further show that there is a strong association between the knowledge and their experience and attitude towards palliative care. Various studies do show that age, past and present experience with death, education regarding the EOL and the year of their training in practical clinical experience had significant influences on their knowledge attitude and experience towards palliative care. Emergency and Oncology Nurses working with Oncology Patients need to possess a better understanding of the practice, policies and protocols of palliative care. It is essential to provide support for the patient and the family throughout the hospital process and ensuring communication to the family when a patient's death becomes imminent so that other family members and/or clergy can be notified (Kubler-Ross, 1969).

5.8 Summary

In this study, Objective 1 was to investigate the knowledge, attitudes and practices of the Emergency and Oncology Nurses regarding palliative care nursing practices for Oncology Patients in three of the Western Cape Provincial Hospitals was discussed. The findings of the quantitative data were discussed in detail with reference to the overall quantitative parts leading to the development of palliative protocols for government hospitals of the Western Cape, South Africa. Steps to ensure rigour and ethical consideration were discussed. The data analysis and the initial interpretation of the data will be discussed in Chapter 6. In the Chapter 7, Objective 2 of the research will be addressed, i.e., to explore the perceptions and experiences of recipients of care (Oncology Patients and their families) regarding the delivery of palliative care. The findings of Part 2: included two qualitative studies, namely, a focus group with the family of the Oncology Patient and semi-structured in depth interviews with Oncology Patients.

CHAPTER 6

FINDINGS OF PHASE 2: CENTRAL AND EMERGING THEMES

6.1 Introduction

This chapter reflects the findings of Phase 2, which included two parts (qualitative studies), namely, Part 1: semi-structured in-depth interviews with the Oncology Patients and Part 2: a focus group interview with the family members of Oncology Patients. These activities were carried out with Objective 2 in mind: to explore the experiences of the Oncology Patients and their families regarding delivery of current palliative care nursing at three government hospitals in the Western Cape Province. Phase 2 addressed two objectives, namely, to explore the experiences of the Oncology Patients, and to explore the experiences of their families, regarding delivery of current palliative care nursing in the three selected Western Cape Provincial Hospitals.

6.2 Central Themes of Phase 2

The central theme of Phase 2 was that the participants, i.e., the Oncology Patients and their family members, had low levels of knowledge regarding expectations in the delivery of palliative care.

6.2.1 Objective 2: Experiences of Oncology Patients and Their families Regarding Delivery of Current Palliative Care Nursing

The following research questions directed Part 2 of the study:

- What are the experiences of Oncology Patients regarding current palliative care practices in the Western Cape Provincial Hospitals?

- What are the experiences of Oncology Patients’ families regarding delivery of current palliative care in the Western Cape Provincial Hospitals?

The following themes emerged from an analysis of the data generated from the semi-structured interviews and the focus group interviews. Participants had limited knowledge of the experience of palliative care. This is indicated in Table 6.1.

Table 6.1: Themes and sub-themes that emerged from Study Objective 2

Themes		**Sub-Themes**	
1.	Experiences in the care of the patient's family members whilst the patient is in the hospital	1.1	Experiences of sharing
		1.2	Experiences of communication
		1.3	Experiences of information sharing
2.	Experiences of visiting the family member in the hospital setting	2.1	Experiences regarding visiting time
		2.2	Experiences regarding seating arrangements
3.	Experiences of professional nursing staff from the family members' perspectives	3.1	Information sharing
		3.2	Collaboration
		3.3	Sensitivity to non-medical and spiritual dimensions of care

6.2.1.1 Theme 1: Experience of Caring for the Oncology Patient's Family Members While in Hospital

Three sub-themes emerged from Theme 1, viz., experiences of sharing, experiences of communication and experiences of information sharing.

> *They put us in a room where we can be together when we receiving the chemo*

> *They are very good people and since we got here they are with my mommy, they treat her well…they give the medication*

> *They tell us when we going for treatment early in the week then we can get prepared*

> *My father is very concerned about his medication and asks what it is for the Professional Nurse says it is for the pain…*

The data analysis in this phase showed that family members of the patient have expectations of the Professional Nurses, to guide and assist their afflicted relative in the hospital setting. The family members freely expressed their interpretation of palliative care and their perceptions of the challenges that their relative experiences in the hospital.

6.2.1.2 Theme 2: Experiences of Visiting the Family Member in the Hospital Setting

Two sub-themes emerged from Theme 2, namely, the experience of visiting the family member regarding the times of visiting and the seating arrangements when they do visit.

> *I would like to see more of my husband but they very strict on visiting time and I work long hours and can only come when someone gives me a lift to the hospital*
>
> *At night if there could be a place we can rest or just sit for now. We… (He* indicates to his sisters*) we sitting in the passage outside the ward because we do not want to get in the way and we do not know where to sit by my father, not enough chairs…*
>
> *I would like that more visits are possible, I would like also not to be chucked out by the security guard my husband needs me, I am looking after two small children I cannot always come on the visiting times…*
>
> *I would like more to come visit my son, he is young he needs the support.*
>
> *When my son needs me I should be there and not be told when I can come in*
>
> *I think they must make more exceptions at least for visitors like us who come from far and when patients are very bad.*
>
> *The beds are very comfortable for our father.*
>
> *The chairs, are very uncomfortable, it could be perhaps softer*
>
> *My experience has been a lot from one hospital to another, a brow-raising experience!*

6.2.1.3 Theme 3: Experiences of Professional Nursing Staff from the Family

Members' Perspectives

Three sub-themes emerged from Theme 3, namely, information sharing, collaboration and sensitivity to non-medical and spiritual dimensions of care.

❖ Collaboration and Team Management

To make these measures of collaboration and team management more effective, the nursing staff should educate, care, promote, advocate and coordinate care in collaboration with the health care team; this includes the patient and the family. There is a need for a specialised body of Professional Nurses with honed non-clinical skills, for example, attention and concern for others, as well as the capacity for understanding, kindness, receptiveness and respect for both patient and family. It is always important to engage in open discussion that is informed by personal maturity. Of equal importance is the ability to collaborate in ongoing team management and of being open to discussion. It is also necessary to show personal maturity, be available to listen carefully, and put to optimum use technical and scientific knowledge as a team manager. The goal of collaboration and teamwork is an increased awareness, and acknowledgement of the complexity of the needs of individuals diagnosed with cancer and their families (Gill & Duffy, 2010:761).

❖ Sensitivity to Non-Medical and Spiritual Dimensions of Care

This is an important factor because it provides the basis for the emotional sensitivity towards and support of the patient and the family. Currently, the patients feel they are being kept in the dark about their poor prognosis and impending death. The patients feel that they are not being treated as a whole and there should be more flexibility to the patient's needs. Research has further shown that the health care clinician is trained to be careful not to say anything to the patient who would make him/her aware that their death is near.

6.2.2 Verification and Member-Checking

Member checking was conducted with family members and Oncology Patients to present the findings of Phase 1 of the study and to verify the themes and recommendations identified. The three themes and sub-themes in Objective 2 are presented in Table 6.1. These were presented to the groups and field notes showed that participants verified and agreed on the emerging themes from the interviews.

6.3 Concluding Statements of the Themes and Sub-Themes from Part 1, Objective 2 of the Study

The following concluding statements from Phase 1 of the study are highlighted below.

- Sensitivity to non-medical and spiritual dimensions of care is important to understand within the particular context.
- This makes it easier for staff members to communicate openly in speaking about a patient's prognosis and obviates lying to the patient when s/he asks outright about his/her condition.

6.4 Summary of Phase 2

This chapter reflects the findings of Phase 2, which included two qualitative studies, namely a focus group discussion with the families of the Oncology Patients and semi-structured in-depth interviews with the Oncology Patients. Objective 2 was realised by exploring the experiences of the Oncology Patients and their families, regarding delivery of current palliative care nursing in three selected Western Cape Provincial Hospitals. Part 2 addressed two objectives: to explore the experiences of the Oncology Patients to explore the experiences of their families, regarding delivery of current palliative care nursing in the three Western Cape Provincial Hospitals. The findings of the research revealed that the patients need a climate of open awareness on the part of the health care clinician—and this includes the Professional Nurse—to be aware of the various emotions and anxieties occasioned by poor prognosis or impending death and to openly acknowledge and address this.

CHAPTER 7

FINDINGS OF PART 3: DEVELOPMENT OF THE PALLIATIVE CARE PROTOCOL

7.1 Introduction

This chapter reflects the findings of Part 3: the development of palliative care protocols using the Nominal Group Technique. This technique integrated data collected in Parts 1, 2 and 3, and information from the literature review. In addition, information was gathered from the Emergency and Oncology Nurses working in the Emergency and Oncology Departments. The information gathered was about Oncology Patients and their families at Groote Schuur, Tygerberg and Victoria Western Cape Provincial Hospitals. Part 3 involved planning for a palliative care protocol. Suggestions were made in Part 2 and were turned into recommendations from the parties responsible for the activities. These recommendations provided the components of the palliative care protocol that was developed.

7.2 Collaboration and Team Management

To make these measures of collaboration and team management more effective, nursing staff should effectively communicate, educate, nurture, promote, advocate and coordinate its implementation in collaboration with the health care team, and should include the patient and family in the process. With this in mind, there is a need for skilled Professional Nurses trained to be attentive and display concern for patients and their families, nurses who are kind, receptive and respectful in their work. It remains important to have be able to conduct discussion with maturity, to be able to collaborate, listen carefully and to manage a team. In addition, technical and scientific knowledge as a team manager is a vital aspect of such a role. The goal of collaboration and teamwork is increased awareness, and the acknowledgement of the complexity of the needs of individuals diagnosed with cancer, as well as the needs of their families (Gill & Duffy, 2010:761).

7.3 Sensitivity to Non-Medical and Spiritual Dimensions of Care

This is an important factor because it forms the basis of the emotional dimension in the support of the patient and the family. Currently, the patients feel they are being kept in the dark about their poor prognosis and impending death. The oncology patient further felt that communication is not being addressed as to non- medical and spiritual dimensions of care as improving recovery, shorter hospital stays, to develop communication skills to listen to them in totality . Research has further shown that health care clinicians are typically careful not to say anything to the patient who will make him/her aware that she/he is close to death. The patients in the research found that they had to ask questions lightly, something with which they felt uncomfortable, just to "trick" staff into revealing details about their prognosis. The oncology patients occasionally felt they are being treated like a burden and when they ask for help this either takes a long time or does not happen .The following extracts illustrates the factor of patient vulnerability

The doctor told me that my illness is very serious today

Has my treatment being stopped?

Why am I not going for treatment?

Am I going home soon?

Some patients found they preferred to ask oncology nurses working on a certain shift because they were "nicer:

Nurses are nice but they so busy I think some of them want to get the work done and go off duty

The other shift is nicer they listen and they call the doctor when we have questions

This place is very busy I find everyone is rushing around me but not with me

The findings of the research revealed that the patients need a climate of open awareness on the part of health care clinicians, including the Professional Nurse, to be aware of the poor prognosis or impending death and openly acknowledge this. Sensitivity regarding the non-medical and spiritual dimensions of care is important to understand within this context. Staff members should be able to exercise caution and care in speaking about the patient’s prognosis, whilst avoiding blatant lies in the event that patients ask outright questions about their condition.

7.4 Limitations of the Study

The study has some limitations, which are discussed below:

- The researcher is of the opinion that in further research in this area, there may be a need to expose more Professional Nurses in the Emergency and Oncology Units of other hospitals, to the same kinds of situations and experiences their colleagues face in the government hospitals.

- The study and protocol were conducted and developed using participants from Western Cape hospitals only. The researcher would have preferred to include more regions of sub-Saharan Africa, but was unable to do so due to time and financial constraints. However, it is expected that the findings will have general application, and that the protocol will be applicable to most government hospitals.

- Apart from the challenges in implementing and sustaining a new protocol, a major concern emerged regarding the scalability of this protocol in other government hospitals beyond the research study. The palliative care protocol must be developed with experience, and the success must be nurtured and developed. Nurturing of a new project is normally done through funding, ideas, education and training. This has been partially achieved in the provision of the establishment of and reporting in this research study.

- Success in new palliative care protocols is achieved in collecting evidence of outcomes, evaluation and research. Important in this regard is sharing and collaboration through scientific publications, and conferences with internal and external groups. This research project reports the first study in the three government hospitals of the Western Cape—the findings are due to be published in an accredited palliative care journal as part of the strategy to increase awareness and share information.

7.5 Recommendations of the Study

Recommendations are made here for nursing practice, nursing education and nursing research.

7.5.1 Main Priorities for Nursing Practice

Scrutiny of questionnaire results indicates that, according to the majority of nurses in both Emergency and Oncology Units, the single most important factor contributing to patient-centred care is the commitment and engagement of senior management. In addition, managers should be committed with a clear vision and strategic plan for how palliative care will fit into daily priorities and how its operation will be processed on a daily basis. The organisational transformation required to achieve the sustained delivery of patient-centred transformation that is needed to achieve the sustained delivery of patient palliative care, will not happen without leadership from the top and their active participation.

7.5.2 Main Priorities for Nursing Education

- Education and Shared Knowledge

Patients are increasingly asking to be involved in their care; this study details their experience according to the interviews held with them as palliative care patients.

- Respect for Patient-Centred Values, Preferences and Expressed Needs

Respect for patient-centred values, preferences and expressed needs, including an awareness of EOL issues, involvement in decision-making, preservation of dignity, and of having, others attend to their needs and respect their wish to be autonomous.

- Coordination and Integration of Care Across Clinical, Ancillary and Support Services

Coordination and integration of care across clinical, ancillary and support services, and the receipt of “front-line care” in the Emergency Unit on the emergency readmission pathway.

- Information, Communication and Education on Clinical Status

Information including communication and education on clinical status, progress (which includes the process of care) in order to facilitate autonomy, self-care and health promotion.

- Physical Comfort and Pain Management

Physical comfort, including pain management and assistance with the activities of daily living, and adaption to make the environment comfortable.

- Emotional Support and Alleviation of Fear and Anxiety

Emotional support and alleviation of fear and anxiety, regarding concerns of clinical status, prognoses, and the effect that illness has on patients and their families and finances.

- Involvement of the Family in Decision-Making

Involvement of the family in decision-making, and awareness and accommodation of their needs as caregivers.

- Transition, Continuity and Information to Promote Patients Self-Care

Transition and continuity as regards information that will help patients care for themselves away from the hospital setting, and the ability to coordinate, plan, and support the transition following discharge.

- Access to Care

Access to care, with attention to time spent waiting in the Emergency Department, placement in a room as an in-patient, and time spent waiting for an appointment or visit in the Out-Patients Department.

- Focus on Cognitive and Behavioural Dimension of Pain and Symptoms

Focus on the cognitive and behavioural dimension of the pain and the symptom experience.

- Attention to Cognitive and Behavioural Dimensions of Pain and Symptoms

Attention to cognitive and behavioural dimensions of pain and symptoms experience in relation to providing specific strategies for effective symptom management.

- Intervention for Effective Training of Health Professionals, Patients and Families as Care Givers

Intervention for effective training of health professional is patients and families as caregivers, to implement their respective roles in pain and symptom assessment and management.

- Bereavement

Following the death of a patient, the Oncology Nurse should offer their condolences to the family and extend assistance with contacting any other family members or individuals, as the family requires. The Oncology or Emergency Professional Nurse should assist the family in removing any jewellery or other items from the patient with care and compassion.

7.5.3 Main Priorities for Nursing Research

The implementation of the palliative care protocol is essential as the next step in furthering the implementation of a valuable strategy to address the knowledge, attitudes and practices of Emergency and Professional Nurses in palliative care for patients and the families within government hospitals in the Western Cape of South Africa, and in other parts of Africa.

Well-designed implementation and evaluation studies in the government hospitals and context are essential to modify the palliative care protocol, in order to improve implementation success or rejection of the protocol:

- These studies should be based on the standard recommendations of practice guidelines.
- Routine studies should be conducted to assess the palliative protocol cost and benefits for the government hospitals.
- The experiences of Oncology Patients and their families within the government hospitals should be further explored using qualitative methodologies.

7.6 Summary

Chapter 7 has provided the findings of Part 3: the development of a palliative care model. This chapter further reflected on the findings of Part 3. The development of palliative care protocols, were done using the Nominal Group Technique. This technique integrated data collected in Parts 1, 2 and 3, with information from the literature review. In addition, information was gathered from the Emergency and Oncology Nurses working in the Emergency and Oncology Departments. Information was collected from the responses of Oncology Patients and their families in the three selected Western Cape Provincial Hospitals. Part 3 involved planning for a palliative care protocol. Suggestions were incorporated in Part 2 and were transformed into recommendations by the parties responsible for the activities. The recommended actions formed the components of the protocol that was developed.

7.7 Conclusion

In conclusion, the study has shown the importance of a palliative care protocol as an issue of immense importance. It is the researcher's belief that a palliative care protocol can be supported in palliative care delivery in the government hospitals by involving the Professional Emergency Nurse and Oncology Nurse as per admission process. The empowerment of the Oncology Patients and their families in decision-making and consulting opportunities will promote ownership, accountability and sustainability of the project. The aim of the development of a palliative care protocol will support the patient and the family experience whilst the patient is in the government hospital. The knowledge and practices, including the experience of the Professional Nurses working in the Emergency unit and Oncology Departments, will be adjusted and regulated, and this in turn will inspire greater trust and confidence in the delivery of palliative care.

CHAPTER 8

DEVELOPMENT OF THE PROPOSED PALLIATIVE CARE PROTOCOLS

8.1 Introduction

This chapter addresses the development of palliative care protocols using Nominal Group Technique. This technique integrated data collected in Parts 1, 2 and 3, and information from the literature review. In addition, information was collected from the Emergency and Oncology Nurses working in the Emergency and the Oncology Departments. Gleaned information was obtained from the Oncology Patients and their families in the three selected Western Cape Provincial Hospitals.

8.2 Patient-and Family-Centred Care Protocol (PFCP)

The Patient-and Family-Centred Care Protocol (PFCP) is a multi-dimensional conceptualisation of patient-centred care that shows how clinical, structural, and interpersonal attributes can collectively influence the patient and the family. The central theme of this protocol focuses on the experience of the patient from his/her perspective, and of their family from their perspective, minimizing vulnerability and maximizing control and respect. According to Edwards & Davies (2002), Professional Nurses need to embrace the foundation of patient-centred care, because Oncology Patients and their families are leaders and expert advocates for their own lives, with goals that coordinate care of the patient who are consistent, timely and offer universal access to care. The main advantage of the PFCP is the involvement of patient and family at all levels of decision-making, concerning the delivery of care. The Patient-and Family-Centred Protocols, about collaborative and respectful relationships (or partnerships) focus on the interaction between the service provider and the recipient of care.

8.2.1 Involvement of the Family

The involvement of the family includes planning and decision-making for the patient, and this is found in many busy oncology practices, including service delivery environments (Honea, Britnall, Given et al., 2008:507). Most oncology teams recognise the importance of the family members and try to include the family caregivers in treatment and planning. Furthermore, the Oncology Nurse can assist Oncology Patients and their families to develop coping strategies and procedures in guiding the family to redefine their roles within the family in order to support the family member with cancer (Buys & McDaniel, 1996:103). The focus group reflected the need to be part of the process, to facilitate knowledge about what is happening to their family member.

- Some participants expressed anxiety about this dynamic:

> *... [want] to help but I do not wish to get in the nurses' or doctors' way.*
>
> *I do not know how to help me am afraid of not knowing...*
>
> *I feel I could have helped my son sooner*
> *As a mother, I felt anxious because time was wasted on waiting for treatment*
>
> *I was annoyed that he was giving my son his condition diagnosis from his point of view I wanted to see the facts.*

- Sensitivity to Non-Medical and Spiritual Dimensions of Care

This is an important factor because it is at the heart of the emotional sensitivity and support of the patient and the family. Currently, the patients feel they are being kept in the dark about their poor prognosis and impending death. Research has further shown that the health care clinician were extra cautious in what they said to the patient, and particularly careful about alerting him/her to the likelihood that his/her death was near. The patients in the research found that they had to ask questions that seemed nonchalant. They did not feel comfortable to do this; they were in fact awkward about using devious means to get closer to truthful information about their condition and their prospects. An extract from a patient's feedback illustrates the point:

The doctor told me that my illness is very serious today.

The patient felt the need to confirm their suspicion, but was not comfortable in doing so.

The findings of the research revealed that the patients need a climate of open awareness on the part of health care clinicians, including the Professional Nurse, to ensure transparency regarding poor prognosis or impending death and openly acknowledge this. The sensitivity of the non-medical and spiritual dimensions of care must be carefully considered in their particular contexts. This will ensure that staff members are able to communicate openly and honestly with patients about their illness.

- Respect for Patients' Needs and Preferences

Of the patients interviewed, more than half believed that they had experienced a breakdown in nursing care that had directly influenced whether their needs and preferences had been addressed. Patients expressed a perceived delay in diagnosis and of treatment.

I was given white tablets for four months to stop the bleeding. If I did not take myself to the doctor and stopped taking the white tablets where would I be?

These patients may have been mistaken about the perceived errors, but it is important to note that for the most part, the patients did not express their concerns about their clinicians and felt the need for reassurance.

The findings of the research reflected that patient who was in possession of information regarding their prognosis expressed this in the form of statements to the nurse, for example:

So I am dying, aren't I?

This kind of question provides a rich opportunity to be honest with the patient and to re-establish in this moment effective nurse-patient communication. Since they have already been told their prognosis, and the Professional Nurse has confirmed this, the patient can be responded to in a unique manner, for example:

> *I know that the doctor has told you a lot of difficult information recently and I am sorry to hear about that.*

This is a suitable initial response to their question, without seeming insensitive by simply repeating the prognosis. Then the job of the nurse is to listen to the patient's response and to take it from there.

The findings of the research reflected further that if the Professional Nurse is honest, s/he is halfway to successful and effective communication, despite not knowing exactly what to say. Professional nurses should never respond in a clichéd or matter-of-fact way or minimalize the situation when it comes to death and dying. Statements such as:

> *Well we are all dying slowly each day anyway.*

Is one such statement; it brushes aside the concerns of the patient.

The findings of the research revealed that Professional Nurses want to show patients they are fully engaged with them and are genuinely interested in their concerns, but feel they lack the skill to communicate.

Interestingly, the patients could identify the genuineness of the Professional Nurse as an important quality and felt that this quality needed no specialised skill. In addition, received wisdom is that, to be genuine is to be actual, real or true, and sincere and honest (Merriam-Webster Dictionary, 2014). To be authentic was described by a patient as:

> *...sincere and free from any dishonesty.*

The Professional Nurse should possess all these qualities in their interaction with patients, because if the patient believes the nurse is authentic, devoted and sincere, they will be more than willing to engage with him/her.

❖ Free Flow and Accessibility of Information

Currently, most of the systems in place are there to detect problems. The patients in this study felt that what should be a free flow of information was too formally reported. For example, patient complaints about medication were rationalised as patients' unwillingness to acknowledge their limited energy, and failure to focus on getting well. However, many found they could talk freely to the nurse about what had occurred so that there could be follow through with anything that needed to be done after contact between patient and nurse.

Free flow of, and accessibility to information should be available at every encounter with the patient, and answers to patient requests given. This will help to show the patient that they are cared for and that information is freely available to them. The researcher noted that free flow of, and accessibility to, information was particularly important because it showed that the Professional Nurse listened to patients' concerns and questions, and remembered to act on them.

The Professional Nurse within palliative care should prioritise communication between patients and their families because this will determine the Quality-of-Care (QOC), and ensure that the whole human being is recognised, and all their needs are met. Given the specific needs of the family members, it appeared to the researcher that to offer a comprehensive and humane care was necessary, and that this meant that improvements had to be made to the hospital infrastructure. When the researcher had verified the focus group interviews it was found that only a limited number of visits were allowed; this concern, it appears, is not being addressed, in the opinion of patients and their families.

The nursing manager as the patient's advocate should value the humanisation of care, taking into account that cultural differences, beliefs and values are important to ensure adequate care for each patient. This is why it is important that proper visitation standards are established and upheld, standards that take into consideration the needs of patients and their families, and not only the standards established by the hospital.

8.2.2 Factors Contributing to Patient-Centred Care

The focus group interviews and supporting literature reviewed for this study indicated six key factors that contribute to achieving patient-centred care within the hospital organisation.

- Key Attributes of Patient Centred Care

A high degree of consensus exists regarding the key attributes of patient-centred care. The findings of the research focused on six core elements:

8.2.2.1 Education and Shared Knowledge

Patients are increasingly asking to be involved in their care. What follows is a record of their experience according to the interviews held with the palliative care patients.

- **Respect for patient-centred values**, preferences and expressed needs. This includes an awareness of EOL issues, patient involvement in decision-making, preservation of their dignity and attending to their needs and their desire for autonomy.

- **Coordination and integration of care across clinical, ancillary and support services**, and receiving "front-line care" in the emergency unit on the emergency readmission pathway.

- **Information, including communication and education, on clinical status and progress**, which includes a process of care that facilitates autonomous self-care and health promotion.

- **Physical comfort, including pain management** and assistance with the activities of daily living, and adaption to make the environment more comfortable.

- **Emotional support and alleviation of fear and anxiety** regarding concerns about clinical status, prognoses and the effect that illness has on patients and their families and finances.
- **Involvement of family in decision-making** and awareness, and accommodation of their needs as caregivers.
- **Transition and continuity with regard to information** that will help patients care for themselves outside the hospital setting, and the ability to coordinate, plan and support the transition following discharge.
- **Access to care**, with attention to time spent waiting in the Emergency Department and placement in a room, in the in-patient setting, as well as time spent waiting for an appointment or visit in the Out-Patients Department.
- **Focus on the cognitive and behavioural dimension** of the pain and the symptom experience.
- **Attention to cognitive and behavioural dimensions** of the pain and symptom experience, and the provision of specific strategies for effective symptom management.
- **Intervention in the effective training of health professionals, patients and families** as caregivers to help them implement their respective roles in pain and symptom assessment and management.
- **Bereavement:** following the death of a patient, the Oncology Nurse should offer their condolences to the family and extend assistance with contacting any other family members or individuals the family requests. The Professional Emergency or Oncology Nurse should assist the family in removing any jewellery or other items from the patient.

8.2.2.2 Leadership

According to the majority of nurses in both Emergency and Oncology, the single most important factor contributing to patient-centred care is the commitment and engagement of senior management. In addition, common sentiment and opinion is that the leadership (i.e., managers) should be committed to a clear vision and strategic plan for how palliative care will fit into daily priorities and be implemented on a daily operational basis. The structural transformation from organisation-, to patient-centred palliative care, can only be achieved if there is buy-in from the top structures of the clinical establishment. As one of the participants put it:

> *There is no chance to succeed without leadership of management…it is not going to happen.*

8.2.3.3 Involvement of Patients' Families

Many patients diagnosed with cancer will eventually need the involvement of a family member. The family forms the foundation of the health care system, supporting advances in treatment in the Out-Patients Ward and the home setting in America (National Cancer, 2016). The contrary can be seen in South Africa; a recent survey in South Africa in a large referral hospital found that the in-patient mortality of medical patients admitted to the General Medicine Service was 11%, with a 12-month post discharge mortality of 35%.

In many cases, this was the predictable picture on discharge, reflecting the burden of patients requiring palliative care in the Acute Medical Service without involvement of a family member as support structure (Van Niekerk, 2015:138). Palliative care requires an urgent shift in the government hospitals, in the approach from curative modalities to comfort-focused care that aims to improve the person's QOL by having family members supporting them through the patient-centred care.

In patient-centred care as in palliative care, the patients and the families are truly involved; both are broadly conceived as essential to and vital in the family as a collaborative unit. The involvement of the family can provide vital support and information throughout the care process. Therefore, the involvement of the company of a loved one during hospitalisation benefits the patient receiving visits from the family member, provides emotional support to the patient, and helps them with their recovery (Sales, 2012:736). The family member plays an important role in the management of the patient at home and the challenge is for increasing numbers of oncology teams, including Professional Nurses, to recognise the role of the family in the treatment of, and planning for the patient (National Cancer Institute, 2016).

The researcher has verified Sales' (2012) statement in noting, when interviewing the family, that only a limited number of visits was allowed, and restrictions were placed on their family wanting to find out more about how to support their family member. The family felt involved, valued and appreciated when the Professional Nurses were honest with them (Lowey, 2008). If the family member asked the Professional Nurse a question, one that they could not reply to, then the correct answer would be to ensure that they follow through and work on a satisfactory answer to the question.

Family members, accompanying patients who have spent time in the health care system, have encountered many individuals along the way, and have witnessed many different types and levels of care provided for the patient. The family and the patient may be sick but they do sense if the nurse is not being himself/herself. In EOL care, an effective nurse-patient relationship is very important to the patient and the family, and this can be successfully fostered because of simply being honest. All of the aforementioned skills can help the nurse engage more effectively with family members.

The findings of the research further suggested that the assistance of the Professional Nurse in engaging effectively with the relatives of the patient is important, so as not to leave the family members out of the conversation. It was further highlighted that greeting the family, making "small talk", and maintaining eye contact with them as well as with the patient, all proved to be valued by patients and their relatives. A patient who feels that their family is being listened to and respected will be a more effective partner in communication. The same applies to the family who, seeing that their loved one is being listened to and respected, will be more likely to communicate with the Professional Oncology or Emergency Nurse as s/he carries out her/his duties. The function of the Professional Nurse is to humanise the care and to prepare the family caregiver and the patient to find alternatives that can not only improve but also enhance the Quality-of-Care (QOC). The findings of the research indicated that family is vital with the patient in the development of their care program. Figure 8.1 illustrates an example of the quality pyramid, reflecting control of levels of care for the patient and the family who are included in the decision-making.

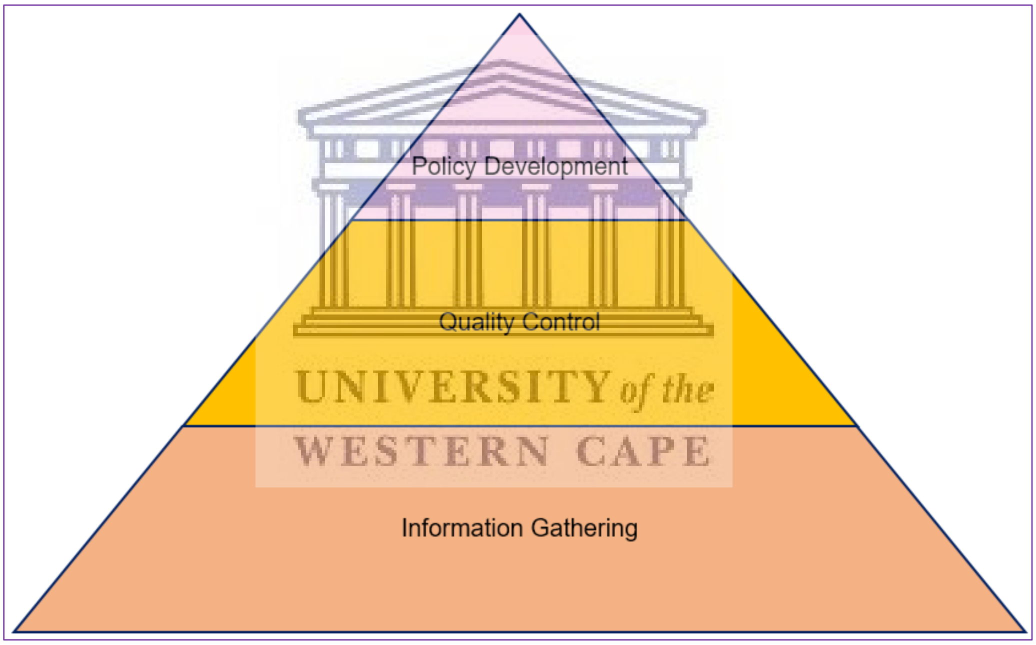


Figure 8.1: Patient- and family-centred care protocol (PFCP)

- Level 1 of the Pyramid: Information Gathering

The findings of the research revealed another level at which the patients and the family meet with the Professional Oncology or Professional Emergency Nurse, depending on where the patient is admitted. At this level, they all participate as full members in the improvement of the QOC. This is done from the beginning planning, implementing-right to the end, i.e., the evaluation of change.

The care demonstrated by the Professional Nurse for the patient, by involving the family, can contribute to the process of gathering information about patient perceptions of care, and assist in analysing and responding to treatment options.

❖ Level 2 of the Pyramid: Quality Control

Patients and families were prepared to participate in key committees dealing with issues. For example, the safety of relatives, patient safety, quality improvement, patient/family education, ethics and research. An example of this involvement is where one patient's family member who is part of an organisation can become a member of the advisory board and meet to identify opportunities or solutions that Professional Nurse Managers may overlook.

❖ Level 3 of the Pyramid: Policy Development

This level is about formulating a shared vision and set of goals for patients and their families, all of whom are involved in developing, since the experiences are shared and lived by them. This process provides the groundwork for the development of local state and national policies.

❖ Care for the Family Members as Caregivers Through a Supportive Work Environment

Care for the caregiver focuses on involving patients and families who have been the cornerstone of palliative care. The findings of the research draw attention to the fact that it is vital to the patient and the family, in the process of caring, to operate in a supportive work environment, in which they are able to have health care professionals with whom they can have open communication. The findings of the research relating to caring for the family as caregivers illustrated that communication is crucial to effective palliative care.

Having a physical presence at the bedside was talked about as crucial to support the patient and particularly the family through the transition, particularly in terms of effective communication. Spending time with the patients and their families constituted a core task in smoothing the transition both in terms of medical and of psychosocial needs. Being present and spending time with patients and their families, through communication and emotional support, was central to caring for the caregivers as family members through a supportive work environment.

❖ Experiences in the Hospital Setting

The researcher noted that when a family member and the patient are dealing with the reality of the hospital, this reality manifests itself as the possibility of death, which is felt with a visceral immediacy. In this way, the emotional needs of the patient and the family, in the care they receive from the Professional Oncology or Emergency Nurse, are crucial. The care must take account of the physiological, but also be emotionally appropriate (Sales, 2012:742).

Further reflections of the family members arising from the focus group discussion:

> *The beds are very comfortable for our father…*
>
> *I feel I could have more time with my husband*
>
> *I am afraid we will not have time to talk because no one talks to us about my Husband*
>
> *At night if there could be a place we can rest or just sit for now* we (he indicates to his sisters), *we sitting in the passage outside the ward because we do not want to get in the way and we do not know where to sit by my father, not enough chairs…*
>
> *I would like that more visits are possible. I would like also not to be chucked out by the security guard, my husband needs me, and I am looking after two small children. I cannot always come on the visiting times.*
>
> *I would like more to come visit my son, he is young he needs the support.*
>
> *I think they must make more exceptions at least for visitors like us who come from far and when patients are very bad.*
>
> *I don't always have money to pay the driver and I am worried what happens when I need to be here and it is late will they call me?*

The researcher has shared this rich information of the family's experiences whilst in hospital, noting during the focus group interviews, the physical difficulties reported by them. The overall experience of the hospital setting is directly linked to rigid infrastructure, and the inflexibility of institutional rules.

8.2.2.4 Systematic Measurement and Feedback

The Oncology Patients who were interviewed often reflected their relatively sophisticated knowledge about cancer pathophysiology and treatment regimens. The patients described episodes of feeling like a partner when they felt included. They said they felt empowered with skills and knowledge, and respected by the Professional Nurses. Patients also appreciated feedback when nurses, for example, open communication. The Professional Nurse informing the patients, of the chemotherapy procedure regarding the timing of pre-chemotherapy, or the speed of the infusion, or the selection of an injection site. By contrast, if patients were not included as partners they felt quite angry when their knowledge was not respected. One participant described her experience with breast cancer:

> *That lump was not there 15 minutes ago—And believe me after having breast cancer I can tell you every lump, bump and cranny, and they just said 'It is not possible.*

For some Oncology Patients, being treated as a partner contributed to the outcome of a sense of well-being. The exchange of such information helps the Oncology Patient become more expert about their disease and treatment, and they are thus better-informed partners in care.

The data indicate that most of the Oncology Patients felt that to be informed is to know. Extracts from a few of the patients' statements, regarding systematic feedback, indicate this:

> *…why it is necessary to do whatever it is they are doing… if they could walk me through everything beforehand and tell me what to expect…*
>
> *I made the decisions. Now I want to be part of the recovery process.*

There was a degree of satisfaction. This was expressed, especially with reference to effective communication between nursing staff and families, more particularly with regard to truthfulness of the information provided by the professional:

> *Any medication I ask what it is for, if they do explain immediately.*
>
> *When I need to know something, they call the doctor and the doctor will provide me feedback on the spot in the round, now I am afraid to ask in front of all the doctors.*

8.2.2.5 Supportive Technology

Supportive technology engages patients and their families directly in the care process, by facilitating communication with their caregivers, and by providing adequate access to needed information and decision support tools. Numerous applications of health information technology have emerged in recent years. For example, e-mail and text communication between the patients, the family and the physician's electronic medical system. Web portals enable patients to interact with their physician.

The Health Africa Summit held in 2011 was about supporting health workers, their patients and their families, even in remote rural areas, and about adapting new technologies for health care. It was shown that in homes with no running water or electricity, mobile phones (almost unknown 15 years ago) are used now to provide a sophisticated form of palliative tele-health. Airtime is known to be costly, so families and volunteers in Africa "flash" nurses (missed call) on their mobile phones, and the nurses call them back. Hence, volunteers are mentored, as the family of the patient as caregiver is addressed.

The caregiver is monitored and spoken to, and this increases the opportunities to maximise access to competent care after discharge from the government tertiary hospital, when the patient has been transferred to the comfort and familiar security of their home. The key to the supportive technology is to implement applications gradually in order to avoid fears that new technology will undermine the quality of patient care, and of Professional Nurses’ interaction with patients and caregivers.

8.2.2.6 Strategies for Leveraging Change

Key strategies were identified to overcome barriers and to help leverage widespread implementation of patient centred care. At the organisational level, these key strategies arose from the survey that was conducted with the Emergency and Oncology Nurses.

- **Leadership Development and Training**

The findings of the research reflected that Professional Nurses request leadership and training. Where emphasis should be placed, is on how understanding can be developed, about how to make the decision to refer a patient to the treating physician, and how to incorporate this into managing the transition as autonomous and responsible professionals. Literature does support this, e.g., Kirby (2014:1136) stated the key element of working with an Oncology Patient is the ability to empathise and have the ability to identify with the patient and their family.

The management of emotion was an important nursing skill that needed to be addressed, because this is arguably one of the most under-recognised and underutilised skills, in the context of referral and of transition to palliative care. Nurses can learn from management in this regard and use the expertise of supervisors and doctors, in representing a significant resource in this area and doctors could more actively draw their expertise.

The literature reflected themes from the systematic data collection of the Professional Nurses. It was found that they placed great emphasis on the value of their input into initiating referral. They view their position as being privileged, in that they are close to the patient, and in a position to notice physiological or psychosocial issues that may prompt timely referral. Within this lies the core element of nursing work, in the nurse’s ability to closely observe the patient and to be proactive in terms of communicating with the doctors or other health professionals in the team. Approximately half of the Professional Nurses admitted to wishing to take a more active role in initiating or prompting a referral, where others felt less confident to approach doctors. This willingness to work with doctors directly links to a readiness to assist with positive professional/patient communication, including areas of negotiation, in contexts where doctors frequently struggle to break bad news to patients and their families. The findings of the research revealed that if Professional Nurses had more opportunities to develop as leaders, and to play a role in smoothing the transition and maintaining psychosocial well-being, there would be greater harmony for the patient and the family.

Moreover, it was clear from the data collection, that there was a perceived lack of support, regarding various aspects of their work, from other health professionals. The Professional Nurses stated, as can be seen in the data, that they needed leadership training because of the emotional demands placed on them, in working with Oncology Patients and their family. It is important to note that the sample of Professional Nurses included a representative sector of both Emergency and Oncology Nurses, with different levels of experience, leadership development and training in the three main government hospitals of the Metropole of the Western Cape. As such, the researcher cannot generalise the findings to other nurses in other settings in Africa.

- **Work Satisfaction**

The literature indicates that the Professional Nurse needs work satisfaction, because this relates directly to their own emotional evaluation of experiences during work, and has a significant impact on the Professional Nurse’s decision to remain in the profession (Biton & Tabak, 2002:140). Furthermore, work satisfaction is positively associated with greater professional autonomy and greater control over the practice environment. This includes the use of nursing systems that promote accountability and continuity of care.

In addition, the literature illustrates that other factors related to work satisfaction were patient care, organisation of service, support from managers, good communication and teamwork. Particular emphasis by Professional Nurses working in Emergency and Oncology Wards were the stresses under which they work daily. Examples of these are limited resources and staff shortages; these that may have an impact on the delivery of care to the terminally ill patient and their family, and affect their perceptions about the supportive nature of the work environment. Interestingly, the researcher noted that work satisfaction, in the findings of this study, were coupled to the attitudes of their colleagues, either positively or negatively. These attitudes, it seems, are influenced by demographic factors, for example, age and experience in working in Oncology or Emergency, as well as the degree of work satisfaction and the degree of support in the working environment.

- **Training in Core Palliative Care Skills and Quality Improvement**

For hospitals, clinician groups and other provider organisations that offer palliative care, there needs to be training in quality improvement and standards of quality for the care for the seriously ill. The literature refers to a range of excellent local and national resources for training and quality improvement for health professionals in Africa. In 2008, with the help of the African Palliative Care Organisation, manuals and guidelines have been made available. Among the areas covered in these manuals, is the topic of standards governing the provision of holistic care in the community, and this includes the tertiary government hospitals. Tools in training for quality improvement have been developed and validated in Africa, for example, the African Palliative Care Outcome Scale (Grant, Liz; Downing, Julia; Namukwaya, Elizabeth; Leng, Mhoira, & Murray, Scott, 2011:1136).

The African Palliative Care Outcome Scale is recommended for routine clinical use, including audit and research. The specified researched African Palliative Care Outcome scale have resources that are used to teach clinicians in developed countries where such standards are often lacking. Palliative care training groups have successfully been established at four universities working with regional hospitals. Two of these groups are in South Africa, i.e., Cape Town and the Witwatersrand. An increasing number of postgraduate degrees and undergraduate degrees are now available—the University of Cape Town offers a Postgraduate Diploma in Palliative Care. Palliative care training is being incorporated into the undergraduate nursing curricula in South Africa.

In addition, there has been an exponential increase in palliative care publications. Before 1995, most papers considered specific clinical issues, but since 2006, research has covered the development of outcomes, tools, and nurse-patient perspectives of care, terminal care, drug availability and programme evaluation. However, only four African journals have published articles on palliative care (Downing et al., 2011:1136).

In summary, to offer training in high quality core palliative care skills, there needs to be a framework to support all facets of life for seriously ill patients and their families. In so doing, palliative care skills and knowledge are reconnected with the patients and their families, as well as the Professional Nurse, and this care goes to the roots, to the foundation of the healing profession. This research study has been concerned with the impact that palliative care has on patient outcomes and patient and family experience. Palliative care competency should be considered fundamental to the practice of nursing and total health care. Palliative care skills should be embedded in undergraduate and graduate training curricula, and these courses should include pathways to critical thinking.

- **Practical Tools Derived from an Expanded Evidence Base**

When practical tools are derived from an expanded evidence base, this presents challenges. One of the challenges lies in elevating the norm through strategies at an organisational level, strategies that utilise the experience of innovators. This process could be useful in motivating large-scale implementation of patient-centred care. The research revealed a dearth of local research; this was related to the urgent need for service delivery, with few validated practical outcome tools for expanded evidence-based practice.

The lack of understanding for practical tools to improve an expanded evidence base was visible in the lack of opportunity and resources for local experts to voice their understanding or to apply understanding and generate participation. The collection of routine mortality data reflects improvements, but the evidenced based is not expanded, and still tells us little about the nature of dying. The impact of practical tools derived from evidence-based research includes developing a process for identifying patients who have palliative care needs. Aspects of this process are tools for risk stratification, matching services to the needs identified on assessment, enabling consistent and standardised documentation tools of the domains of evidence-based palliative care, for example, symptom control, symptom burden, depression, cognition, functional status, and family caregiver needs. Last but not least, is that information be stored as an electronic record, to be used in developing protocols for referral to specialty palliative care, when needed.

If new health research confirms the findings of evidence-based research in mortality, then it is critical to systematically identify the actual "active ingredients", which could be modified for intervention related to pain and symptoms of those in need of palliative and EOL care. Technologies improve data collection and data entry efficiency should be continually updated and striven for. The National policy and health leaders require a sound knowledge base and national directory to understand the complex burden and the best models of practical tools of care.

8.3 Conclusion

The findings of the research ultimately revealed that palliative care must address total pain and suffering. Widely accessible, attainable and effective analgesia is a great-unmet need in Africa and Sub-Saharan Africa, and morphine supplies are insufficient. For palliative care to be accessible, attainable, effective and sustainable, it must be integrated and prioritised in mainstream services such as government hospitals, alongside curative and preventative care. Palliative care is possible in surroundings of poverty, by building on community capital, acknowledging patients as having great physical, psychosocial, emotional and spiritual needs, and to providing psychological and spiritual support to the patient and their family from the admission, and this includes bereavement support for the family. The results of the study provide detailed information about the palliative care patient and family experience. There is also information regarding Emergency and Oncology Nurses—their knowledge, attitudes and perceptions of caring for palliative care patients admitted to three selected government hospitals. The study also demonstrates the important role of palliative care in the hospital. Emergency and Oncology Nurses need adequate resources and knowledge about symptom management and palliative care, in order to provide good care to these cancer patients during their hospital stay. In addition, early integration of palliative care in the Emergency Department may optimise the QOC.

8.4 Limitations

There are some limitations to this study. First, symptoms and care needs were assessed by Professional Nurses and not by the Oncology Patients. Secondly, the perspectives of families, and their focus on how to care for their family members as patients, were influenced by the fact that considerations about what led to hospitalisation, was not discussed with the families. The focus was on the symptoms and not on the care needs of both patient and family. Even though the researcher had held meetings with persons in charge of the ward, the word “palliative” was used in different ways and its definition was not uniform. At the time of the study, one of the 3 hospitals did not have an Oncology Section for the patients and their families. The Oncology Patients were treated in Emergency and then referred to a larger government hospital, and the families were not consulted on the way forward. In conclusion, it is worth noting some study limitations that occurred because of the qualitative and quantitative being contextualised in the daily experiences of the participants in the research. Thus, the results do not allow for generalisations, though they can be used in similar situations.

8.5 Recommendations

The South African Department of Higher Education should also take the initiative to integrate palliative care into the medical and the nursing curricula, and encourage nurses to develop specialised tracks in this field. Masters programmes should also be offered by the South African universities, to improve the qualification of the health care professionals and to motivate research in the palliative care field. The researcher hopes that this study will be used to deepen knowledge and reflection on the concrete needs of family caregivers in the hospital context. In this sense, there is a need to develop further research in this line, and involve a larger number of families.

REFERENCES

Barnett, J. “Focus group tips for beginners”, [Online], Available from: http://www-tcall.tamu.edu/orp.orp1.htm.

Beck, C.T. 2013 Handbook of qualitative nursing research. TJ International Ltd.Padstow, Cornwell.

Becker, R. 2009. Palliative care principles nursing and End-of-Life care. Nursing Times.

Lo, B., Quill, T. & Tulsky, J. 1999. Discussing palliative care with patients. *Annals of Internal Medicine*, 130(9):744-749.

Bernard, L., Quill, T. & Tulsky .1999. Discussing palliative care with patients”, British journal of nursing, vol. 19, no. 12, pp. 772-774.

Bickman, L & Rog, D. 2009. Applied social research methods. SAGE.

Connell, T., Fernandez, R.S., Griffiths. R., Tran, D., Agar, M., Harlum, J., Langdon, R. 2010. “Perceptions of the impact of health-care services provided to palliative care clients and their carers”. *International Journal of Palliative Nursing*, vol. 16, no. 6, pp. 274-84.

Crane, R.A., Wilson, P.C. & Behrens, G. 1990,. Pain control in hospice home care: Management guidelines. *American Journal of Hospice Care*, vol. 7, no. 6, pp. 39-42.

Doyle, D. 1984. The management of far advanced illness, 1st edition, Charles Press Publishers, Pennsylvania.

Dunlop, H. 1990. Terminal Care Support, first edition, Oxford, United States.

Family Health International. 2009. “Palliative Care Strategy for HIV and other diseases”, February, pp. 1-35.

Finkelstein, D. 1989. Job stress and satisfaction among the staff members at a cancer center. *Cancer*, vol. 64, no. 4, pp. 975-982.

Finola Gill, A.D. 2010, “Caring for cancer patients on non-specialist wards”, *British Journal of Nursing*, vol. 19, no. 12, pp. 761-762.

Georges, J., Grypdonck, M. & Casterle, D.D. 2002, “Being a palliative care nurse in an academic hospital: a qualitative study about nurses’ perceptions of palliative care nursing”, *Journal of Clinical Nursing*, vol. 11, no. 6, pp. 785-793.

Guillemin, M. & Gillam, L. 2004, Ethics, reflexivity, and “ethically important moments” in research.

Qualitative Inquiry, 10(2), pp 261-280.

Gonzalez, L. 2013. "Need to rethink palliative care in South Africa", http://www.health-e.org.za/2013, pp. 1-5.

Grant, L., Downing, J., Namukwaya, E., Leng, M. & Murray, S.A. 2011. "Palliative care in Africa since 2005: Good progress, but much further to go. *BMJ Supportive & Palliative Care,* vol. 1, no. 2, pp. 118-122.

Gray, G. & Berger, P. 2007. "Pain in women with HIV/AIDS." *Pain,* vol. 132, no. Suppl 1, pp. S13-21.

Gubrium, J.F., Holstein, J.A, Marvasti, A.B., & McKinney. K.D.2012. SAGE hand book of interview research the complexity of the craft. Thousand Oaks, CA SAGE.

Guest, G.J. & Mitchell, M.M. 2013. Collecting qualitative data. Thousand Oaks, CA: SAGE Harding, H 2012. The validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale.

Gutierrez, K.M. 2005. Critical care nurses' perceptions of and responses to moral distress. *Dimensions of Critical Care Nursing,* vol. 24 no. 5, pp. 229-241.

Honea, N.J., Brintnall, R., Given, B., Sherwood, P., Colao, D.B., Somers, S.C. & Northouse, L.L. 2008. "Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden." *Clinical Journal of Oncology Nursing*, vol. 3, no. 12, pp. 507-516.

Jenkins, V., Fallowfield, L. & Saul, J. 2001. "Information needs of patients with cancer: results from a large study in UK cancer centers", *British Journal of Cancer,* vol. 84, no. 1, pp. 48-51.

Kendall, S. 2007, "Witnessing tragedy: nurses' perceptions of caring for patients with cancer." *International Journal of Nursing Practice*, vol. 13, no. 2, pp. 111-20.

Khader, K., Jarrah, S. & Alasad, J. 2010. "Influence of nurses' characteristics and education on their attitudes towards death and dying: A review of literature." *International Journal of Nursing and Midwifery*, vol. 2, no. 1, pp. 1-9.

Kirby, E., Broom, A. & Good, P. 2014. "The role and significance of nurses in managing transitions to palliative care: a qualitative study", *BMJ Open*, vol. 4, no. 9, p. e006026.

Kinghorn, S. & Gamlin, R. 2001, Palliative Nursing, 1st edition, Balilliere Tindall, Toronto.

Kirk, P., Kirk, I., Kristjanson, L.J. 2004. "What do patients receiving palliative care for cancer and their families want to be told?" A Canadian and Australian qualitative study. *BMJ*, vol. 328, no. 7452, p. 1343.

Knott, J.E., Wild, E. 1986. “Anticipatory grief and reinvestment.” In: Rando T A (Eds) Loss and grief. Lexington Books USA, pp. 55-60.

Kubler-Ross, E .1969. “On death and dying.What the dying has to teach doctors, nurses, clergy and their own families,” New York: Scribner.

Lichter, I. 1991. “Some psychological causes of distress in the terminally ill.” *Palliative Medicine*, vol. 5, pp. 138-146.

Lofland, J. & Lofland, L. 1995. “Analyzing social settings. A guide to qualitative observation and analysis.” 3rd edition. Belmont, CA: Wadsworth.

Lowey, S. 2015, “Nursing Care at the End-of-life” in Nursing Care at the End-of-life. What Every Clinician Should Know, ed. Sunny Textbooks, 1st edition Pressbooks.com, New York, pp. 7-129.

Matiti, M.R., Trorey, G.M. 2008. “Patients’ expectations of the maintenance of their dignity.” *Journal of Clinical Nursing*, vol. 17, no. 20, pp. 2709-2717.

McMillan, S.S., Kendall, E., Sav, A., King, M.A., Whitty, J.A., Kelly, F. & Wheeler, A.J. 2013. “Patient-centered approaches to health care: A systematic review of randomized controlled trials.” *Medical Care Research and Review*, vol. 70, no. 6, pp. 567-596.

Mazor, K.M., Roblin, D.W., Greene, S.M., Lemay, C.A., Firneno, C.L., Calvi, J., Prouty, C.D., Horner, K. & Gallagher, T.H. 2012. “Toward patient-centered cancer care: Patient perceptions of problematic events, impact, and response.” *Clinical Oncology*, vol. 30, no. 15, pp. 1784-1790.

Medland, J, Howard-Ruben, J. Whitaker, E. 2004. “Fostering psychological wellness in oncology nurses: addressing burnout and social support in the workplace.” *Oncology Nursing Forum*, vol. 31, no. 1, pp. 47-54.

Menzies, K., Murray, J. & Wilcock, A. 2006, *International Journal of Palliative Nursing*, 447.

Meredith, C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C.R. & Fallowfield, L. 1996, “Information needs of cancer patients in west Scotland: cross sectional survey of patients’ views”, *BMJ* (Clinical research ed.), vol. 313, no. 7059, pp. 72.

Mok, E, & Chiu, P.C. 2004. “Nurse-patient relationships in palliative care.” *Journal of Advanced Nursing* 48(5), 475-476.

Moreland, S.S., Lemieux, M.L. & Myers, A. 2012. “End-of-life care and the use of simulation in a baccalaureate nursing program.” *International Journal of Nursing Education Scholarship*. Vol 9, no. 1., Retrieved 22 Jul. 2018, from doi:10.1515/1548-923X.2405.

Mwangi-Powel, F., Callaway, M. & Tallis, V. 2012. Palliative Care in Southern Africa.

Mok, E. & Chiu, P.C. 2004. “Nurse and patient relationships in palliative care”, *Journal of Advanced Nursing*, vol. 48, no. 5, pp. 475-483.

Moore, P. & Lawrie, T. 2013, “Communication skills training for healthcare professionals working with people who have cancer”, *Cochrane Libary*, vol. 3, pp. 1-81.

Murray, S.A., Grant, E., Mwangi-Powell, F. 2005. “Health in Africa: Time to wake up to cancer’s toll.” *BMJ* vol. 331, no. 7521, p. 904.

Namasivayam, P., Lee, S., O’Connor, M. & Barnett, T. 2014, “Caring for families of the terminally ill in Malaysia from palliative care nurses’ perspectives”, *Journal of Clinical Nursing*, vol. 23, no. 1, pp. 173-180.

National Cancer Institute 2016, “Family Caregivers in Cancer: Roles and Challengers (PDQ) Health Professional Version”, pp. 1-2.

National Consensus Project. Clinical Practice Guidelines for Quality Palliative Care. 2nd ed. Brooklyn, NY.

National Council for Hospice and Palliative Care Services (NCHPCS) 2002. Fulfilling lives. Rehabilitation in palliative care. NCHPS, London.

Nursing Act No. 33 of 2005. Regulations relating to the scope of practice of persons who are registered or enrolled under the Nursing Act, Pretoria: Government Printing Office.

Osman, A., Barrios, F.X., Osman, J.R., Schneekloth, R. & Troutman, J.A. 1994. “The Pain Anxiety Symptoms Scale: psychometric properties in a community sample.” *Journal of Behavioral Medicine*, vol. 17, no. 5, pp. 511-522.

Owen, S., 2002. “Relieving stress in palliative care staff.” *Palliative Care Today*, vol. 9, no. 1, pp. 4-5.

Pavlish, C. & Ceronsky, L. 2009, “Oncology nurses’ perceptions of nursing roles and professional attributes in palliative care”, *Clinical Journal of Oncology Nursing*, vol. 13, no. 4, pp. 404-412.

Payne, S.A., Dean, S.J. & Kalus, C. 1998, “A comparative study of death anxiety in hospice and emergency nurses”, *Journal of Advanced Nursing*, vol. 28, no. 4, pp. 700-706.

Peteet, J.R., Murray-Ross, D., Medeiros, C., Walsh-Burke, K., Rieker, P. & Poirier, P. & Sossong, A. 2010, “Oncology Patients’ and nurses’ perceptions of caring”, CONJ-RCSIO, no. Spring, pp. 62-65.

Parry, M. 2011. “Student nurses’ experience of their first death in clinical practice.” *International journal of Palliative Nursing*, 17(9):446-451.

Payne, R.A. 2000. “Relaxation techniques. A practical handbook for the healthcare professional.” Churchill Livingstone, London.

Pettigrew, A.C., Dienger, M.J. & King, M.O.B. 2011. "Nursing students today: Who are they and what are their learning preferences?" *Journal of Professional Nursing*, vol. 27, no. 4, pp. 227-236.

Polit, D. &, Beck, C.T. 2010. "Essentials of Nursing Research," 8th edition: Gulanick and Myers.

Radwin, L, 2000, "Oncology Patient's Perceptions of Quality Nursing Care", *Research in Nursing & Health*, vol. 23, pp. 179-190.

Ranjit, K. 2011, Research Methodology a step-by -step guide for beginners, 3rd edition Sage Publications, India.

Reid, J., McKenna, D. & McCone, T.V. 2010, "An exploration of the experience of cancer cachexia: what patients and their families want from healthcare professionals", *European Journal of Cancer Care*, vol. 19, no. 5, pp. 682-689.

Reinhard, S.C., Given, B., Petlick, N.H. & Bemis, A. 2008. "Supporting Family Caregivers in Providing Care." In: Hughes RG, editor. Patient Safety and Quality: An Evidence-Based Handbook for Nurses. P p. 26-28,Rockville (MD): Agency for Healthcare Research and Quality (US); 2008 Apr. Chapter 14. Available from: https://www.ncbi.nlm.nih.gov/books/NBK2665/.

Rittman, M.D., Paige, P., Rivera, J., Sutphin, L., 1997. "Phenomenological study of nurses caring for dying patients*." Cancer Nursing*, vol. 20, no. 2, pp.115-119.

Ross, M, 1996. "The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care." *Journal of Advanced Nursing*, vol. 23, no. 1, pp. 126-137.

Rothstein, H., Sutton, A. & Borstein, M. (Eds). 2005. "Publication Bias in Meta-Analysis." https://idostatistics.com/rothstein-sutton-borenstein-2005-publication-bias-meta-analysis/. Retrieved 22 Jul. 2018, New York: John Willey.

Rushton, C.H., Kaszniak, A.W., Halifax, J.S. 2013. "Addressing moral distress: application of a framework to palliative care practice." *Journal of Palliative Medicine*, CA: SAGE.

Salam-White, L., Hirdes, J.P., Poss, J.W., Blums, J. 2014. "Predictors of emergency room visits or acute hospital admissions prior to death among hospice palliative care clients in Ontario: A retrospective cohort study." *BMC Palliative Care*, vol, 13, no. 1, p. 35.

Sapir, R., Catane, R., Kaufman, B., Isacson, R., Segal, A., Wein, S. & Cherny, N.I. 2000, "Cancer patient expectations of and communication with oncologists and oncology nurses: the experience of an integrated oncology and palliative care service", *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care In Cancer*, vol. 8, no. 6, pp. 458-463.

Schumacher, K.L., Stewart, B.J., Archbold, P.G., Caparro, M., Mutale, F. & Agrawal, S. 2008 "Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment." *Oncology Nursing Forum*, vol. 35, no. 1, pp, 49-56.

Sekse, R.J.T., Hunskår, I. & Ellingsen, S. 2018." The nurse's role in palliative care: A qualitative meta-synthesis." *Journal of Clinical Nursing*, vol. 27, no. 1-2, pp. e21-e38.

Shaller, D. 2007. "Patient-centered care: What does it take?" *Commonwealth Fund New York*; p.26.

Stajduhar, K.I., Thorne, S.E., McGuinness, L., Kim-Sing, C. 2010. "Patient perceptions of helpful communication in the context of advanced cancer." *Journal of Clinical Nursing*, vol. 19, no. 13-14, pp. 2039-2047.

Sapsford, R. 2006. "Data collection and analysis," 2nd edition.CA: SAGE

Spadley, J.P. 1980. "Participant observation." Rinehart & Winston.

Speck, P. 2012. "Working with dying people." In: Obholzer, A., Zagier-Roberts, V. (Eds) 2002. "The unconscious at work." Brunner-Routledge .London.

Spross, J. 1996. "Coaching and suffering: The roles of the nurse in helping people face illness. In Suffering." Jones and Jones. Boston.

South African Nursing Council. 1984: R2598, as amended. No 50 of 1978. Pretoria: Government printing office.

Tappen, R.M. 2011. "Advanced Nursing Research from Theory to Practice." Jones & Bartlett Learning.

Trippet, L. 1931. "The Method of Statistics." London: Williams& Norgate.

Tse, J.W.K., Hung, M.S.Y. & Pang, S.M.C. 2016. "Emergency nurses' perceptions of providing end-of-life care in a Hong Kong emergency department: A qualitative study. *Journal of Emergency Nursing* vol. 42, no. 3, pp. 224-232.

Van Niekerk, L., Raubenheimer, P.J. 2014. "A point-prevalence survey of public hospital inpatients with palliative care needs in Cape Town, South Africa." *South African Medical Journal*, vol. 104, no. 2, pp. 138-141.

Verschuur, E.M., Groot, M.M., Van der Sande, R. 2014. "Nurses' perceptions of proactive palliative care: A dutch focus group study." *International Journal of Palliative Nursing*, vol. 20, no. 5, pp. 241-245.

Ward-Griffin, C.M.P. 2000, "Relationships between Nurses and Family Care givers: Partners in Care?" *Advances in Nursing Science*, vol. 22, no. 3, pp. 89-103.

Welman, J.C., Kruger, Mitchell (Ed) 2007. Research Methodology, Oxford University Press Southern Africa.

White, K.R., Roczen, M.L., Coyne, P.J. & Wiencek, C. 2014. "Acute and critical care nurses' perceptions of palliative care competencies: A pilot study." *Journal of Continuing Education in Nursing*, vol. 45, no. 6, pp. 265-277.

Wholihan, D. 1992, "The value of reminiscence in hospice care. 11(6):249-253." *European Journal of Palliative Care*, vol. 6, no. 11, pp. 249-253.

Wilkie, D. & Ezenwa, M. 2012, "Pain and Symptom Management in Palliative Care and at End-of-life", *Nursing Outlook*, vol. 60, no. 6, pp. 357-364.

Wilkinson, J.M. 1988. Moral in nursing practice: experience and effect." *Nursing Forum*, vol. 1, no. 23, pp. 16-29.

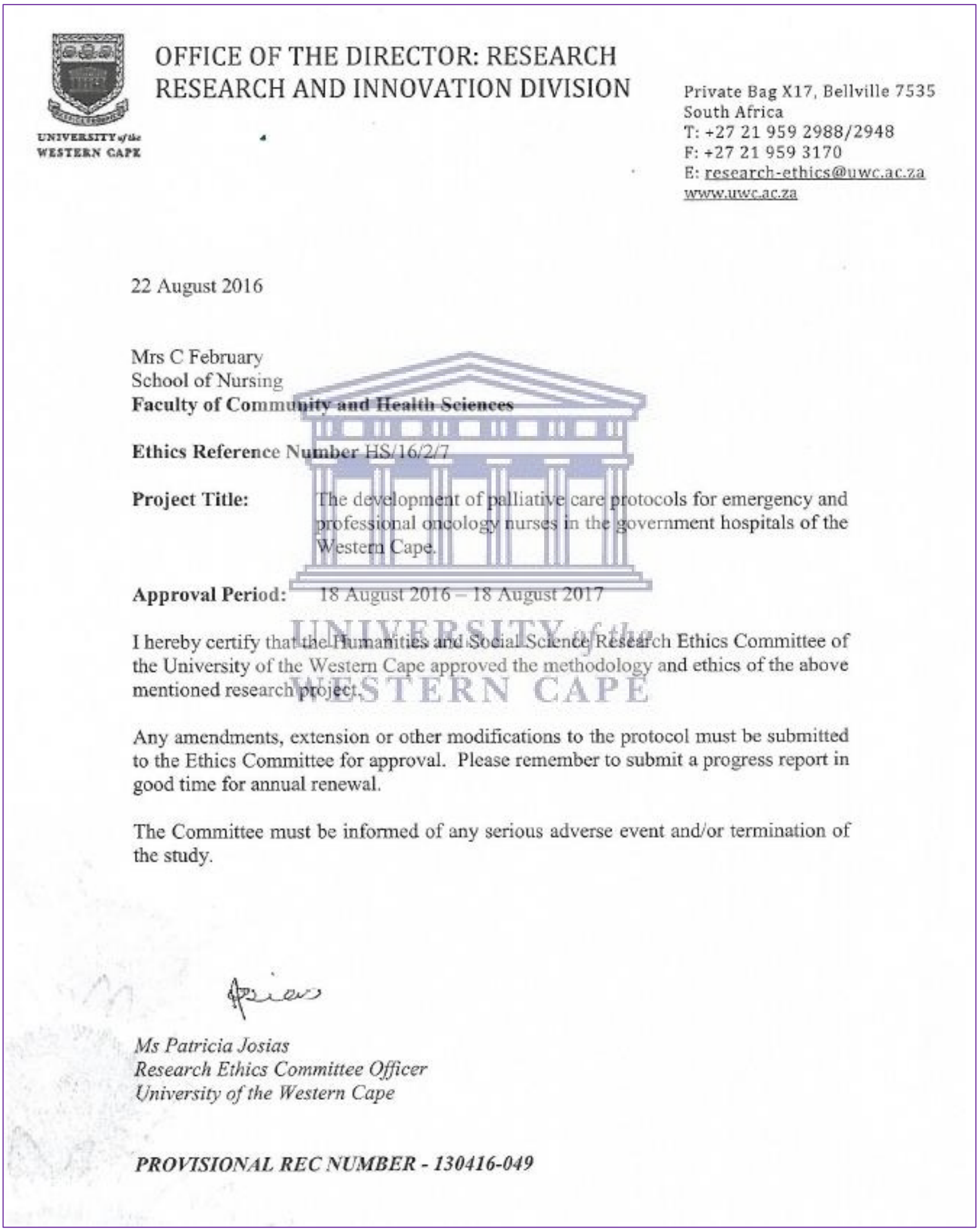
Wilson, D.M., Goodwin, B.L. & Hewitt, J.A. (Ed). 2011. An Examination of Palliative or End-of-Life Care Education in Introductory Nursing Programs across Canada. .

Wittenberg,E.,Goldsmith,J.V.,Williams,Y.& Lee.A. Caring for family caregivers a Pilot Test of online COMFORT training module for undergraduate nursing students. *Journal of Cancer Education November 2018.*

Wright, C. 2006. Hospice and Palliative Care in Africa a review of developments and challenges, first edition, Oxford, Lancaster.

APPENDIX A

ETHICS CLEARANCE CERTIFICATE



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22 August 2016

Mrs C February
School of Nursing
Faculty of Community and Health Sciences

Ethics Reference Number HS/16/2/7

Project Title:	The development of palliative care protocols for emergency and professional oncology nurses in the government hospitals of the Western Cape.
Approval Period:	18 August 2016 – 18 August 2017

I hereby certify that the Humanities and Social Science Research Ethics Committee of the University of the Western Cape approved the methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

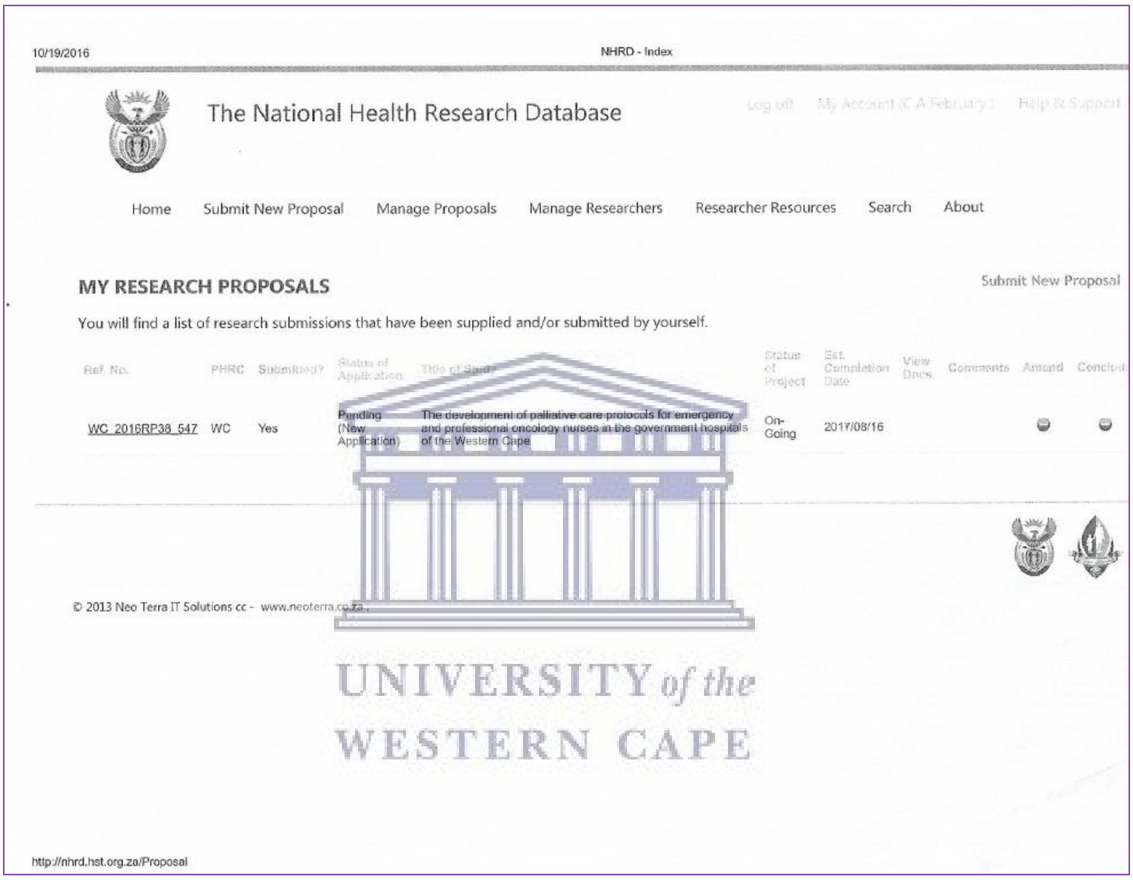
The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

PROVISIONAL REC NUMBER - 130416-049

APPENDIX B

RESEARCH PROPOSAL SUBMITTED TO THE NATIONAL HEALTH RESEARCH DATABASE



10/19/2016 NHRD - Index

The National Health Research Database

MY RESEARCH PROPOSALS

You will find a list of research submissions that have been supplied and/or submitted by yourself.

Ref. No.	PHRC	Submitted?	Status of Application	Title of Study	Status of Project	Est. Completion Date	View Docs.	Comments	Amend	Conclud
WC_2016RP38_547	WC	Yes	Pending (New Application)	The development of palliative care protocols for emergency and professional oncology nurses in the government hospitals of the Western Cape	On-Going	2017/08/16			●	●

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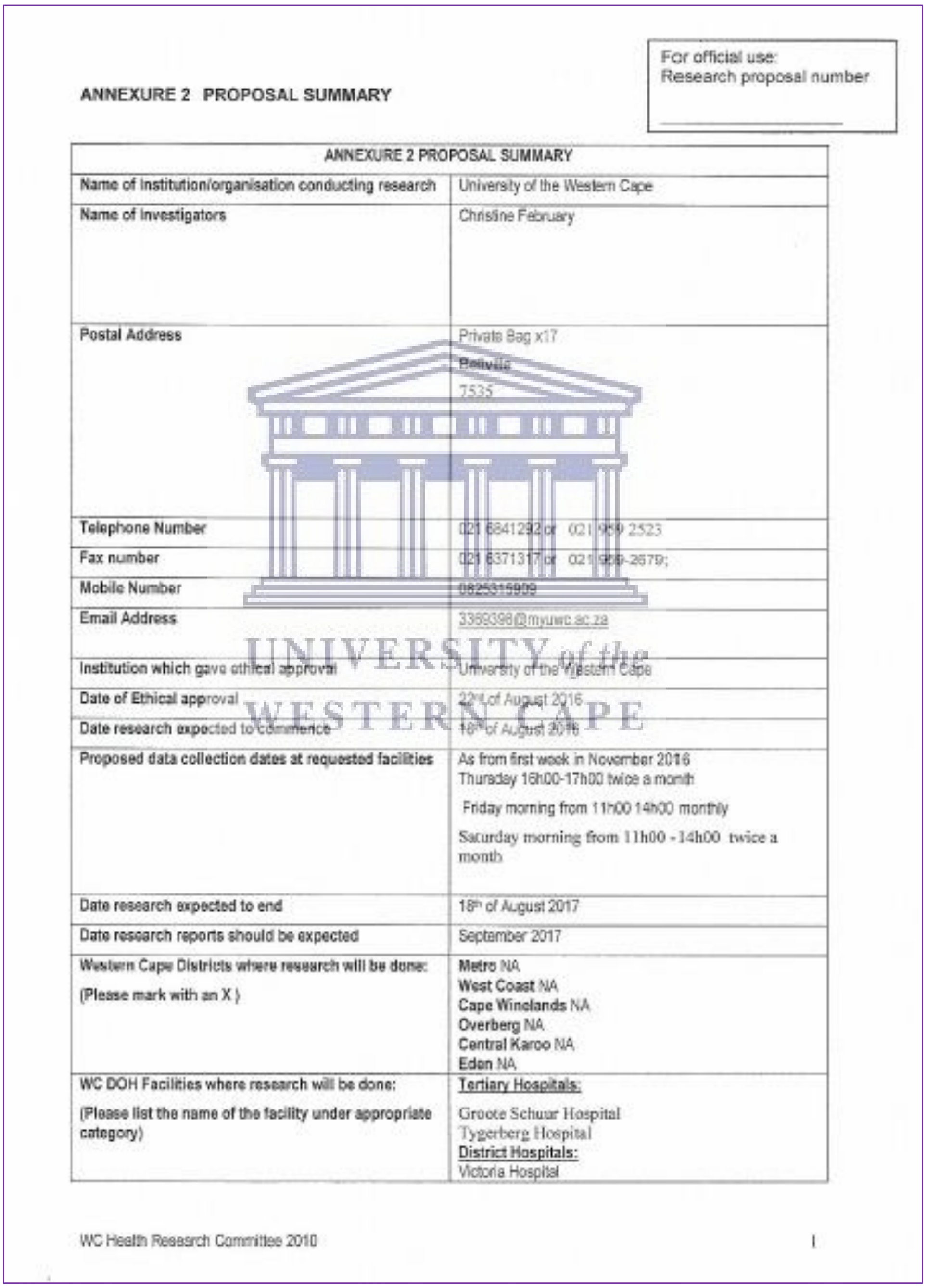
http://nhrd.hst.org.za/Proposal

APPENDIX C

RESEARCH PROPOSAL SUBMITTED TO THE DEPARTMENT OF HEALTH FACILITIES



For official use:
Research proposal number

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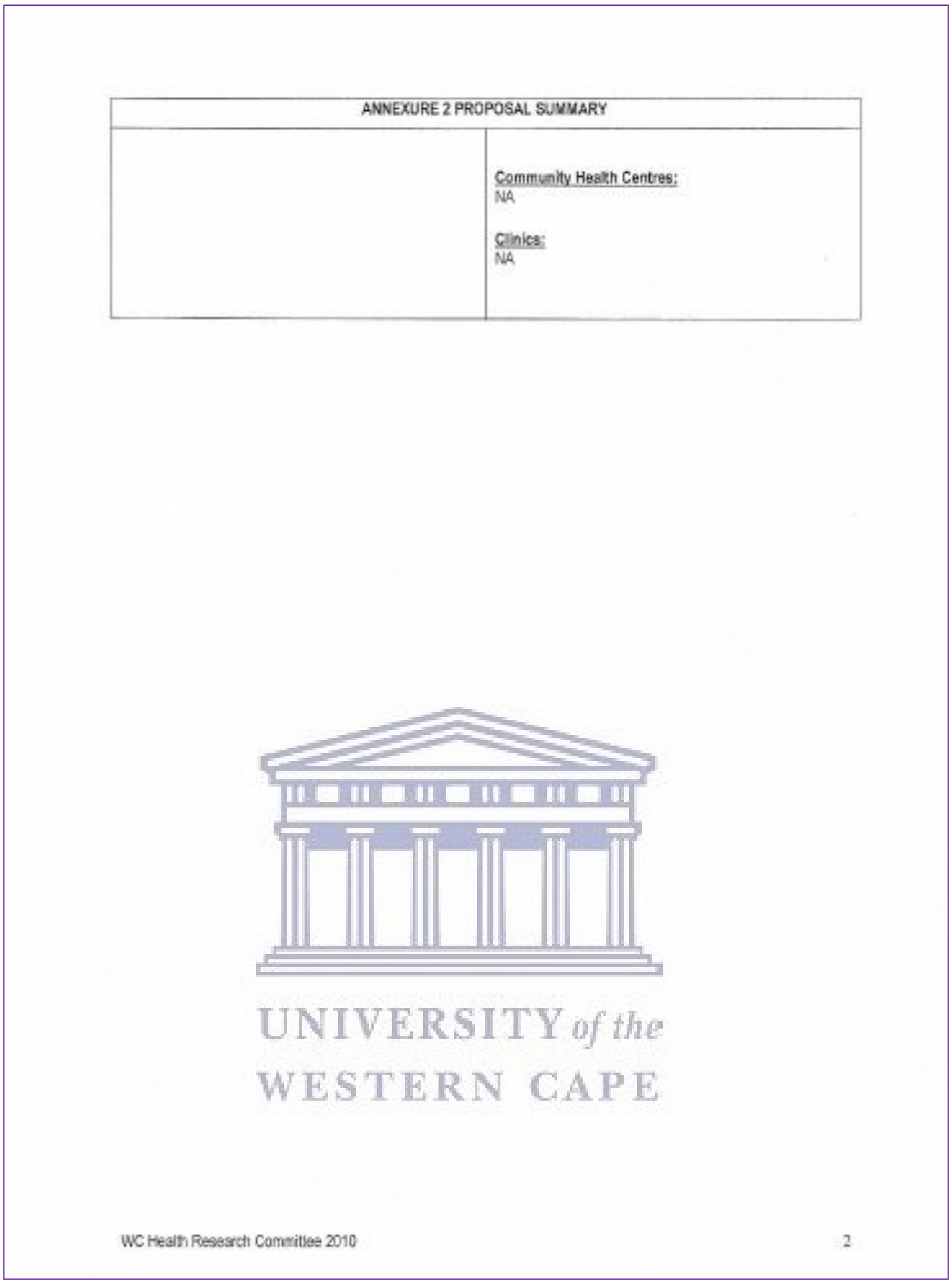
ANNEXURE 2 PROPOSAL SUMMARY

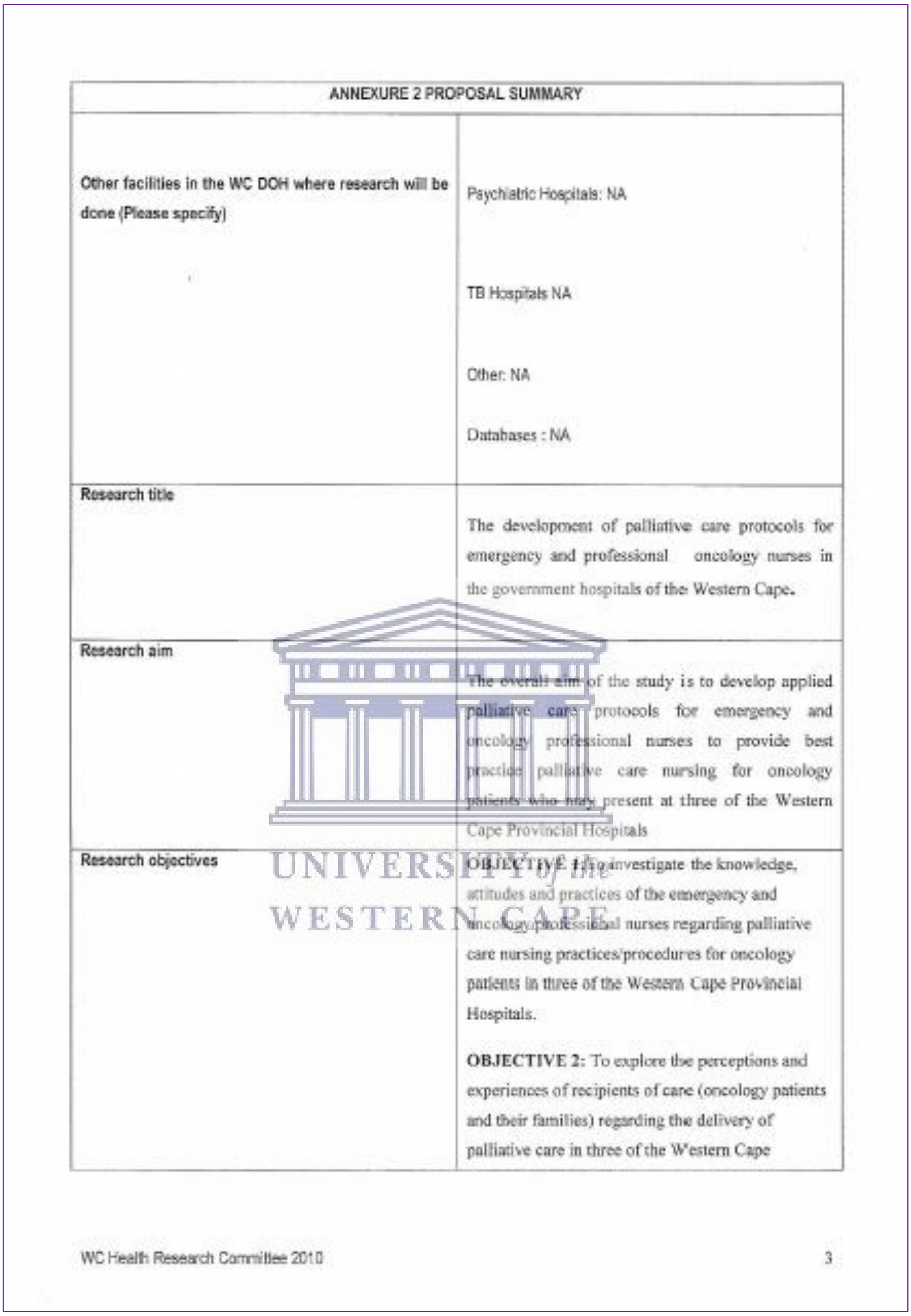
ANNEXURE 2 PROPOSAL SUMMARY	
Name of institution/organisation conducting research	University of the Western Cape
Name of investigators	Christine February
Postal Address	Private Bag x17 Bellville 7535
Telephone Number	021 6841292 or 021 959 2523
Fax number	021 6371317 or 021 959-2679;
Mobile Number	0825316909
Email Address	3369398@myuwc.ac.za
Institution which gave ethical approval	University of the Western Cape
Date of Ethical approval	22nd of August 2016
Date research expected to commence	18th of August 2016
Proposed data collection dates at requested facilities	As from first week in November 2016 Thursday 16h00-17h00 twice a month Friday morning from 11h00 14h00 monthly Saturday morning from 11h00 - 14h00 twice a month
Date research expected to end	18th of August 2017
Date research reports should be expected	September 2017
Western Cape Districts where research will be done: **(Please mark with an X)**	**Metro** NA **West Coast** NA **Cape Winelands** NA **Overberg** NA **Central Karoo** NA **Eden** NA
WC DOH Facilities where research will be done: **(Please list the name of the facility under appropriate category)**	**Tertiary Hospitals:** Groote Schuur Hospital Tygerberg Hospital **District Hospitals:** Victoria Hospital

WC Health Research Committee 2010 1



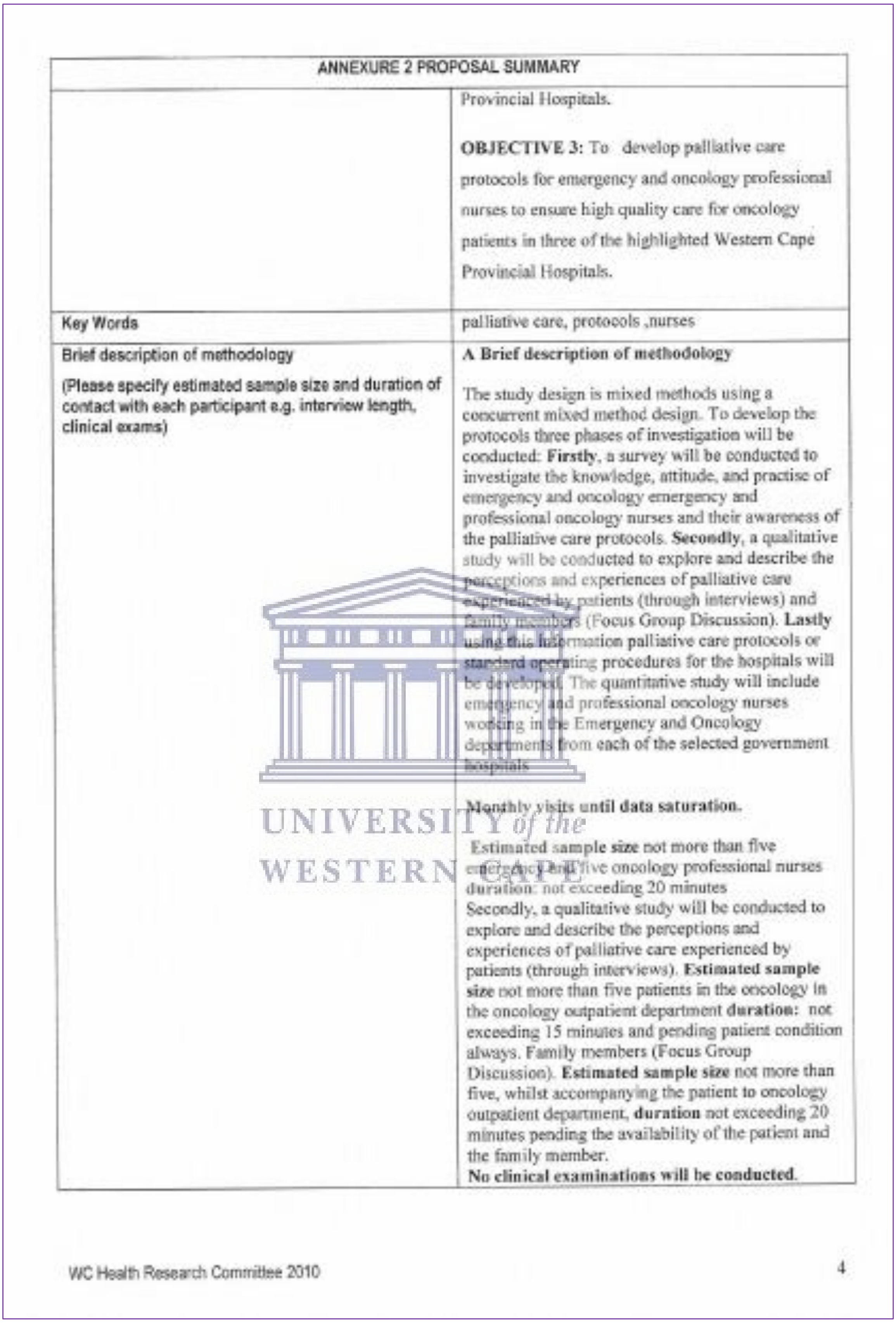
ANNEXURE 2 PROPOSAL SUMMARY	
	Community Health Centres: NA **Clinics:** NA

WC Health Research Committee 2010 2



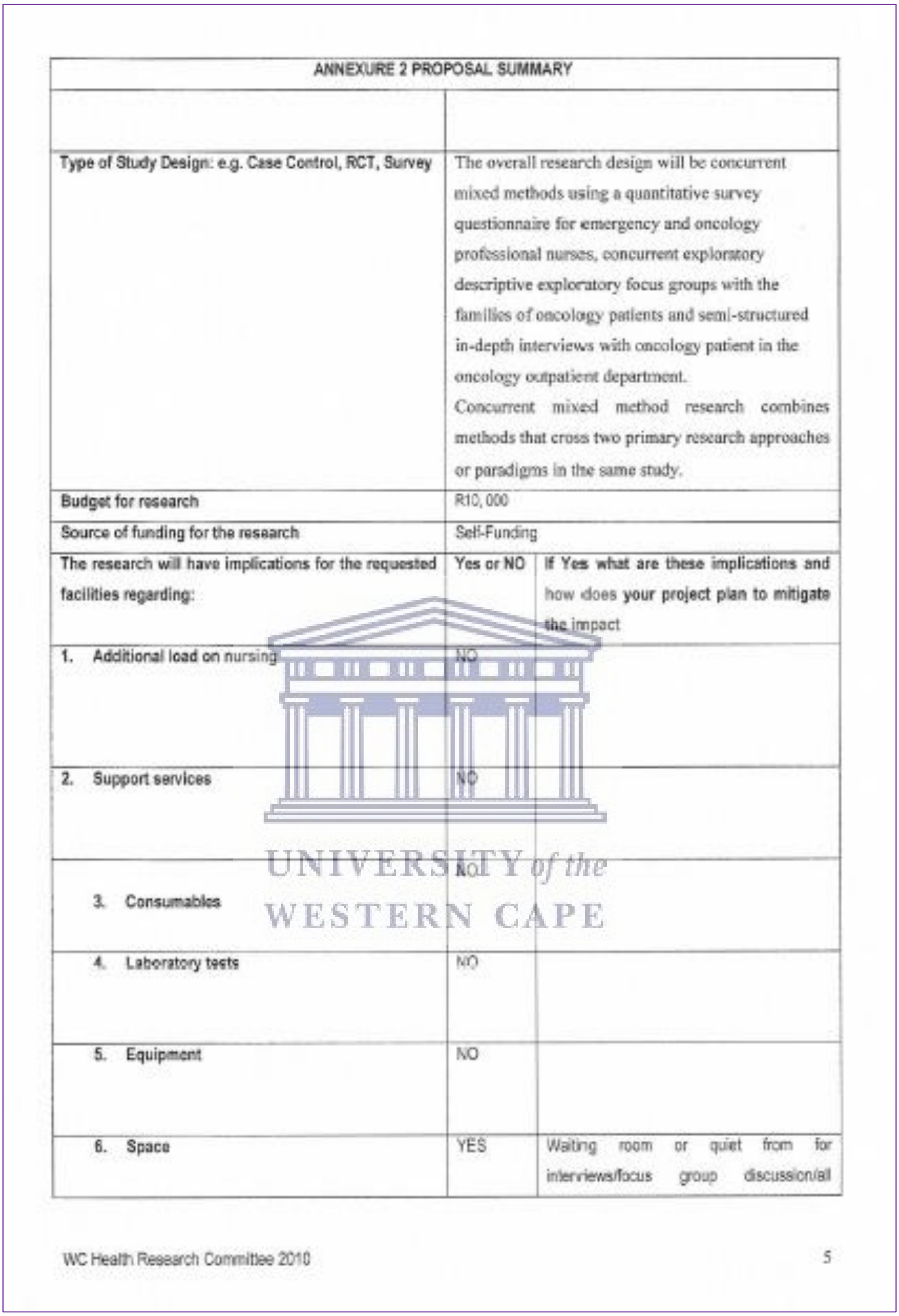
ANNEXURE 2 PROPOSAL SUMMARY	
Other facilities in the WC DOH where research will be done (Please specify)	Psychiatric Hospitals: NA TB Hospitals NA Other: NA Databases : NA
Research title	The development of palliative care protocols for emergency and professional oncology nurses in the government hospitals of the Western Cape.
Research aim	The overall aim of the study is to develop applied palliative care protocols for emergency and oncology professional nurses to provide best practice palliative care nursing for oncology patients who may present at three of the Western Cape Provincial Hospitals
Research objectives	**OBJECTIVE 1:** To investigate the knowledge, attitudes and practices of the emergency and oncology professional nurses regarding palliative care nursing practices/procedures for oncology patients in three of the Western Cape Provincial Hospitals. **OBJECTIVE 2:** To explore the perceptions and experiences of recipients of care (oncology patients and their families) regarding the delivery of palliative care in three of the Western Cape

WC Health Research Committee 2010 3



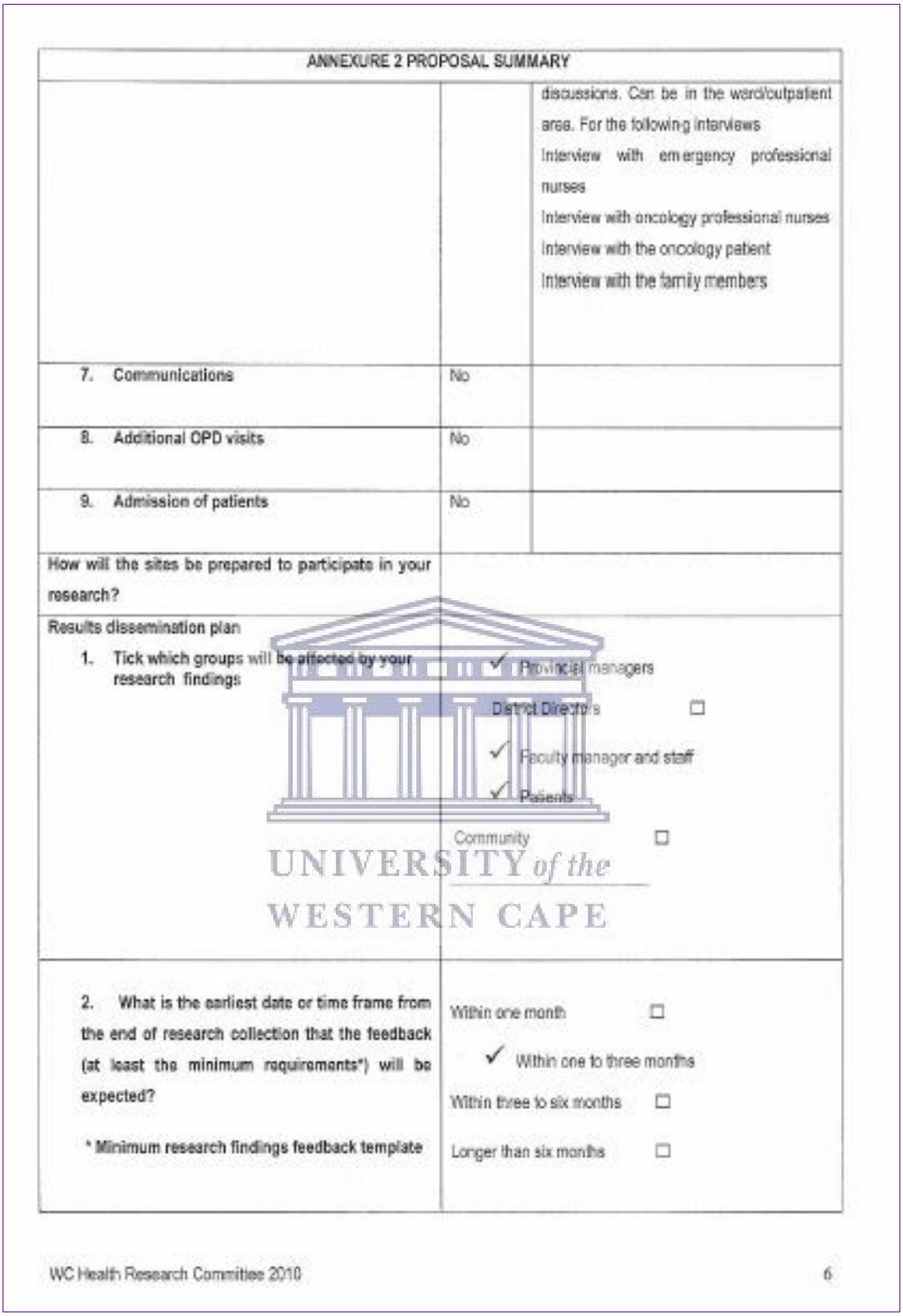
ANNEXURE 2 PROPOSAL SUMMARY

	Provincial Hospitals. **OBJECTIVE 3:** To develop palliative care protocols for emergency and oncology professional nurses to ensure high quality care for oncology patients in three of the highlighted Western Cape Provincial Hospitals.
Key Words	palliative care, protocols ,nurses
Brief description of methodology (Please specify estimated sample size and duration of contact with each participant e.g. interview length, clinical exams)	**A Brief description of methodology** The study design is mixed methods using a concurrent mixed method design. To develop the protocols three phases of investigation will be conducted: **Firstly**, a survey will be conducted to investigate the knowledge, attitude, and practise of emergency and oncology emergency and professional oncology nurses and their awareness of the palliative care protocols. **Secondly**, a qualitative study will be conducted to explore and describe the perceptions and experiences of palliative care experienced by patients (through interviews) and family members (Focus Group Discussion). **Lastly** using this information palliative care protocols or standard operating procedures for the hospitals will be developed. The quantitative study will include emergency and professional oncology nurses working in the Emergency and Oncology departments from each of the selected government hospitals **Monthly visits until data saturation.** Estimated **sample size** not more than five emergency and five oncology professional nurses **duration**: not exceeding 20 minutes Secondly, a qualitative study will be conducted to explore and describe the perceptions and experiences of palliative care experienced by patients (through interviews). **Estimated sample size** not more than five patients in the oncology in the oncology outpatient department **duration:** not exceeding 15 minutes and pending patient condition always. Family members (Focus Group Discussion). **Estimated sample size** not more than five, whilst accompanying the patient to oncology outpatient department, **duration** not exceeding 20 minutes pending the availability of the patient and the family member. **No clinical examinations will be conducted.**



ANNEXURE 2 PROPOSAL SUMMARY		
Type of Study Design: e.g. Case Control, RCT, Survey	The overall research design will be concurrent mixed methods using a quantitative survey questionnaire for emergency and oncology professional nurses, concurrent exploratory descriptive exploratory focus groups with the families of oncology patients and semi-structured in-depth interviews with oncology patient in the oncology outpatient department. Concurrent mixed method research combines methods that cross two primary research approaches or paradigms in the same study.	
Budget for research	R10, 000	
Source of funding for the research	Self-Funding	
The research will have implications for the requested facilities regarding:	**Yes or NO**	**If Yes what are these implications and how does your project plan to mitigate the impact**
1. Additional load on nursing	NO	
2. Support services	NO	
3. Consumables	NO	
4. Laboratory tests	NO	
5. Equipment	NO	
6. Space	YES	Waiting room or quiet from for interviews/focus group discussion/all

WC Health Research Committee 2010 5



ANNEXURE 2 PROPOSAL SUMMARY		
		discussions. Can be in the ward/outpatient area. For the following interviews Interview with emergency professional nurses Interview with oncology professional nurses Interview with the oncology patient Interview with the family members
7. **Communications**	No	
8. **Additional OPD visits**	No	
9. **Admission of patients**	No	
How will the sites be prepared to participate in your research?		
Results dissemination plan 1. **Tick which groups will be affected by your research findings**	✓ Provincial managers District Directors ☐ ✓ Faculty manager and staff ✓ Patients Community ☐	
2. **What is the earliest date or time frame from the end of research collection that the feedback (at least the minimum requirements*) will be expected?** *** Minimum research findings feedback template**	Within one month ☐ ✓ Within one to three months Within three to six months ☐ Longer than six months ☐	

WC Health Research Committee 2010 6

APPENDIX D

PERMISSION TO CONDUCT RESEARCH AT GROOTE SCHUUR HOSPITAL

Western Cape Government
Health

GROOTE SCHUUR HOSPITAL
Enquiries: Dr Bernadette Eick
E-mail : Bernadette.Eick@westerncape.gov.za

Mrs C. February
School of Nursing - UWC

E-mail: 3369398@myuwc.ac.za

Dear Mrs February

RESEARCH PROJECT: The Development of palliative Care Protocols for Emergency and Professional Oncology Nurses in the Government Hospitals of the Western Cape

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research, which is valid until **18 August 2017.**

Please note the following:

a) Your research may not interfere with normal patient care.
b) Hospital staff may not be asked to assist with the research.
c) No additional costs, to the hospital should be incurred i.e. Lab, consumables or stationary may be used.
d) **No patient folders may be removed from the premises or be inaccessible.**
e) Please discuss the study with the HOD before commencing.
f) Please introduce yourself to the person in charge of an area before commencing.
g) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
h) Confidentiality must be maintained at all times.
i) Should you at any time require photographs of your subjects, please obtain the necessary indemnity forms from our Public Relations Office (E45 OMB or ext. 2187/2188).
j) Should you require additional research time beyond the stipulated expiry date, please apply for an extension.
k) **On completion of research, please submit a copy of the publication or report.**

I would like to wish you every success with the project.

Yours sincerely

DR BERNADETTE EICK
CHIEF OPERATIONAL OFFICER
Date: 4th November 2016
BE/vms

C.C. Mr L. Naidoo, Dr F. Conrad, Mr A. Mohamed

G46 Management Suite, Old Main Building,
Observatory 7925

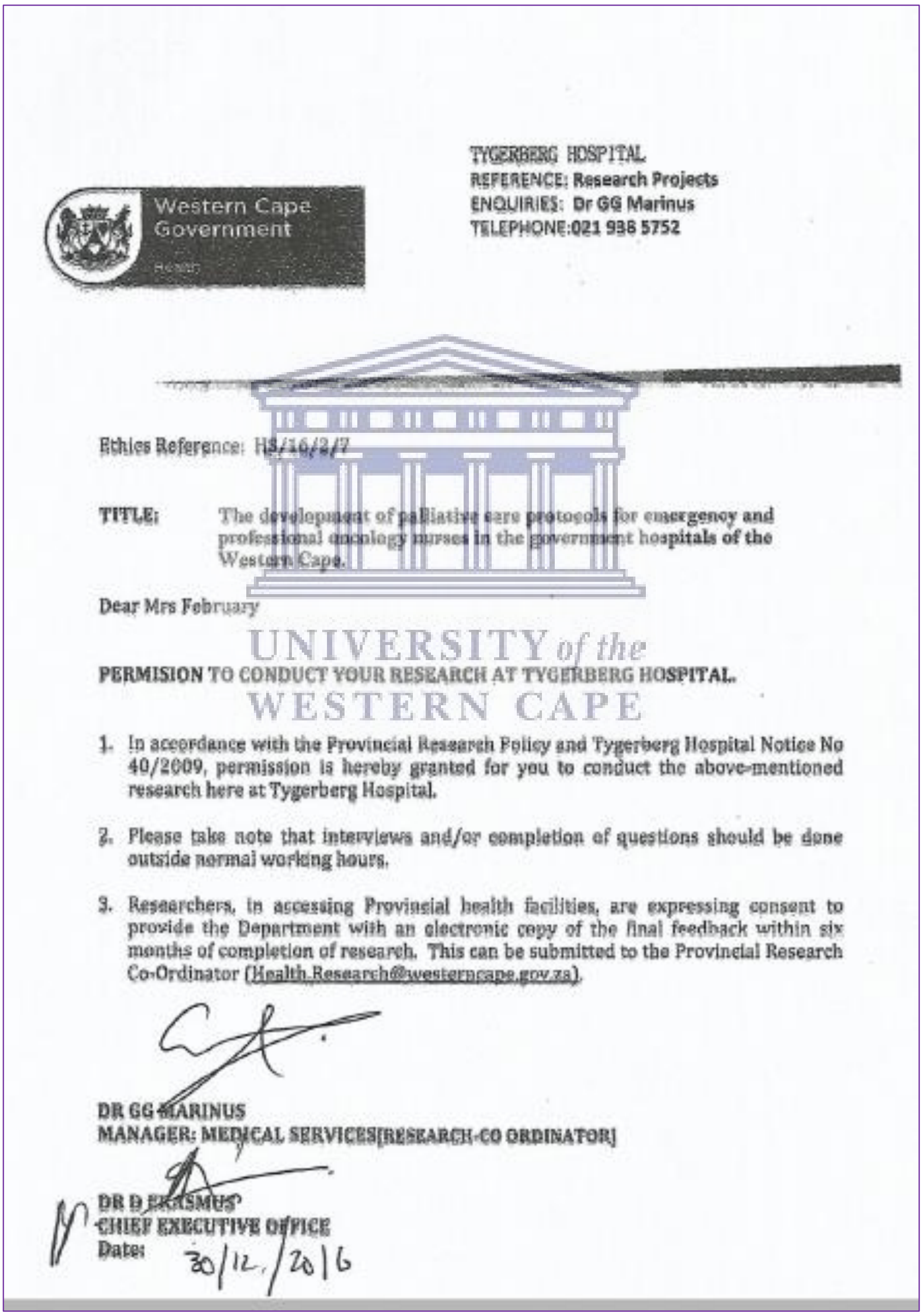
Private Bag X,
Observatory, 7935

Tel: +27 21 404 6288 fax: +27 21 404 6125

www.capegateway.go.v.za

APPENDIX E

PERMISSION TO CONDUCT RESEARCH AT TYGERBERG HOSPITAL



Western Cape Government
Health

TYGERBERG HOSPITAL
REFERENCE: Research Projects
ENQUIRIES: Dr GG Marinus
TELEPHONE:021 938 5752

Ethics Reference: HS/16/2/7

TITLE: The development of palliative care protocols for emergency and professional oncology nurses in the government hospitals of the Western Cape.

Dear Mrs February

PERMISION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

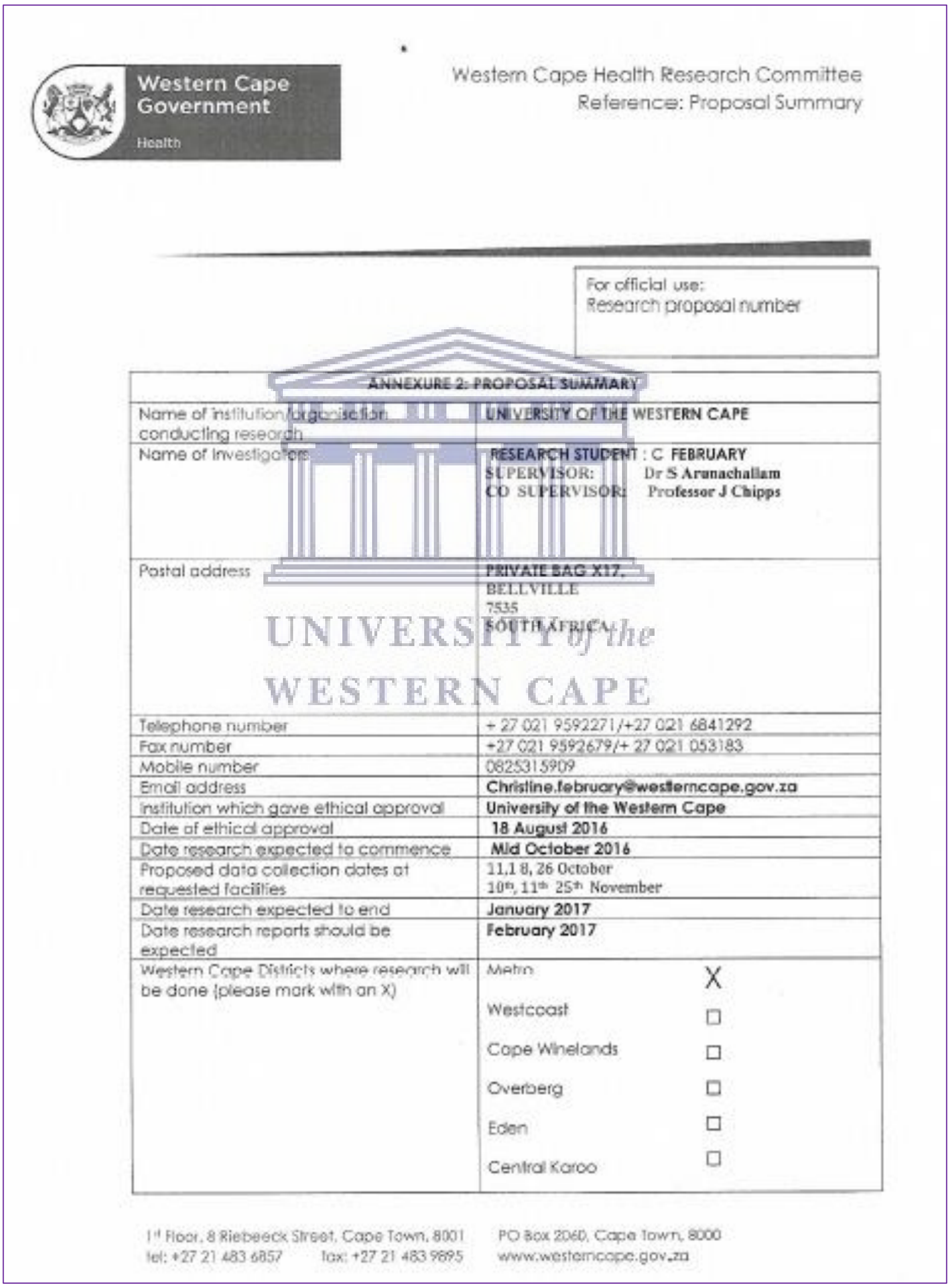
1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Please take note that interviews and/or completion of questions should be done outside normal working hours.
3. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

DR GG MARINUS
MANAGER: MEDICAL SERVICES[RESEARCH-CO ORDINATOR]

DR D ERASMUS
CHIEF EXECUTIVE OFFICE
Date: 30/12./2016

APPENDIX F

RESEARCH PROPOSAL SUBMITTED TO THE WESTERN CAPE GOVERNMENT HEALTH RESEARCH COMMITTEE



Western Cape Government
Health

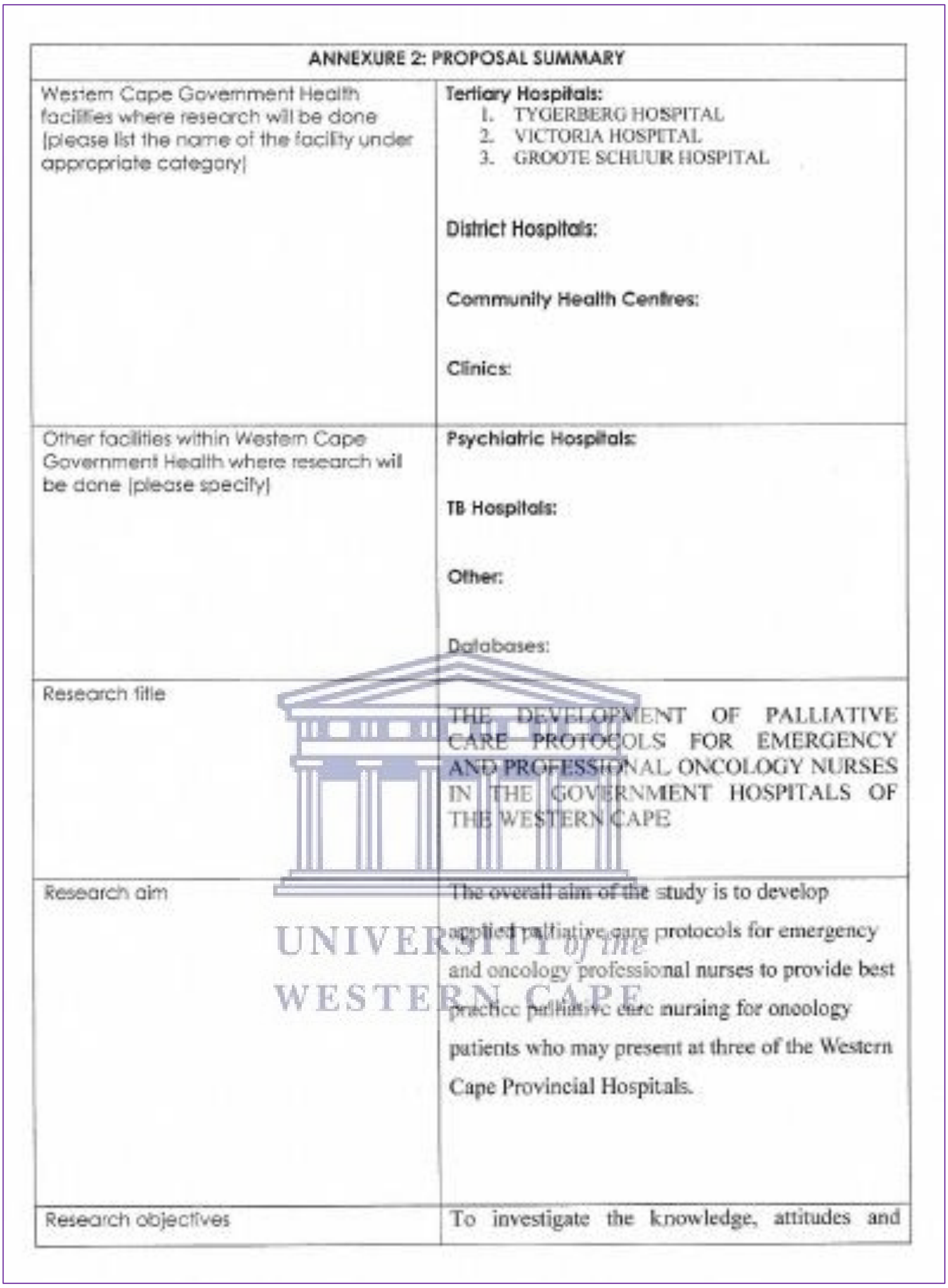
Western Cape Health Research Committee
Reference: Proposal Summary

For official use:
Research proposal number

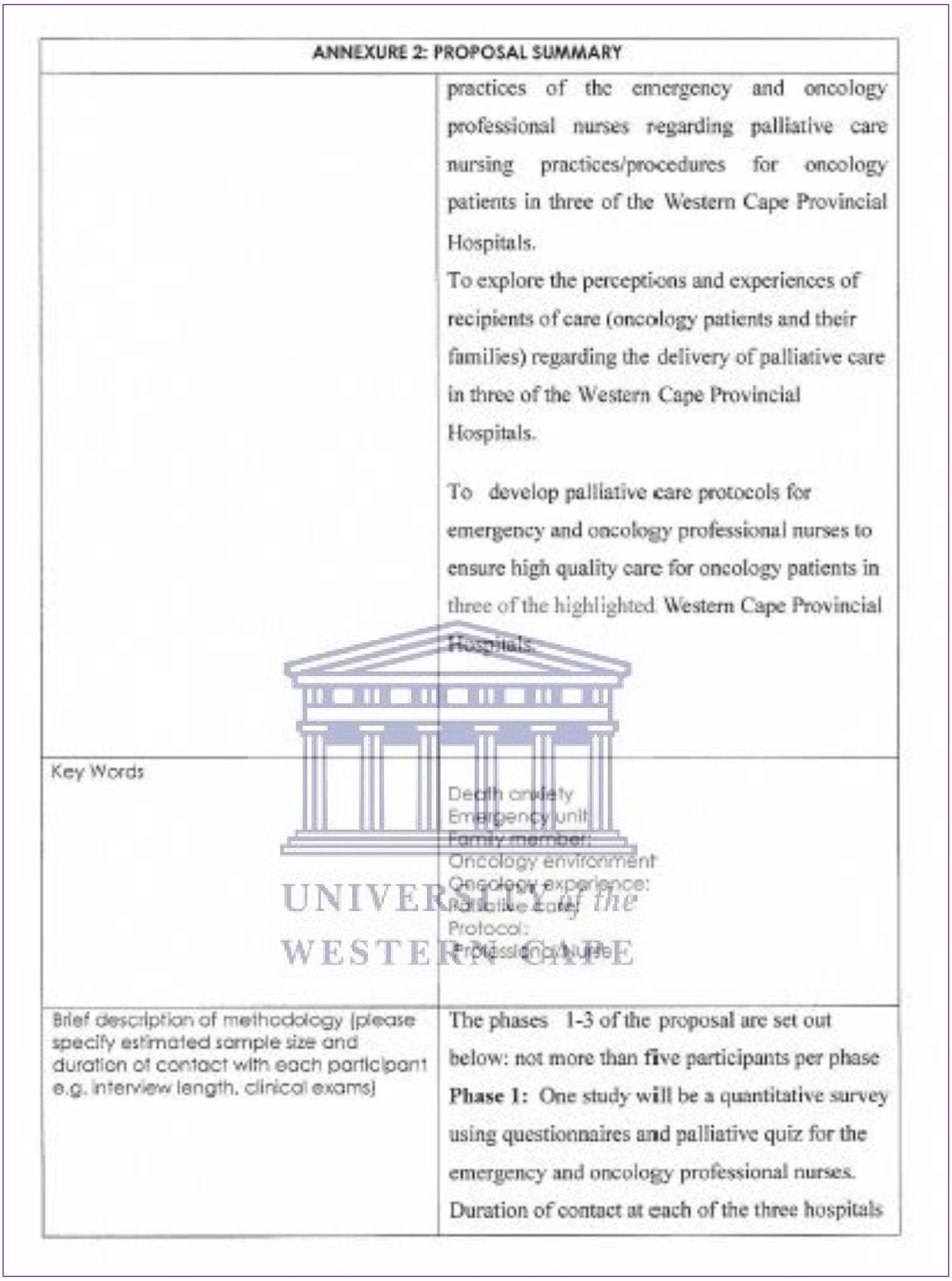
ANNEXURE 2: PROPOSAL SUMMARY	
Name of institution/organisation conducting research	**UNIVERSITY OF THE WESTERN CAPE**
Name of investigators	**RESEARCH STUDENT** : C **FEBRUARY** SUPERVISOR: **Dr S Arunachallam** CO SUPERVISOR: **Professor J Chipps**
Postal address	**PRIVATE BAG X17,** BELLVILLE 7535 SOUTH AFRICA
Telephone number	+ 27 021 9592271/+27 021 6841292
Fax number	+27 021 9592679/+ 27 021 053183
Mobile number	0825315909
Email address	**Christine.february@westerncape.gov.za**
Institution which gave ethical approval	**University of the Western Cape**
Date of ethical approval	**18 August 2016**
Date research expected to commence	**Mid October 2016**
Proposed data collection dates at requested facilities	11,1 8, 26 October 10th, 11th 25th November
Date research expected to end	**January 2017**
Date research reports should be expected	**February 2017**
Western Cape Districts where research will be done (please mark with an X)	Metro X Westcoast ☐ Cape Winelands ☐ Overberg ☐ Eden ☐ Central Karoo ☐

1st Floor, 8 Riebeeck Street, Cape Town, 8001
tel: +27 21 483 6857 fax: +27 21 483 9895

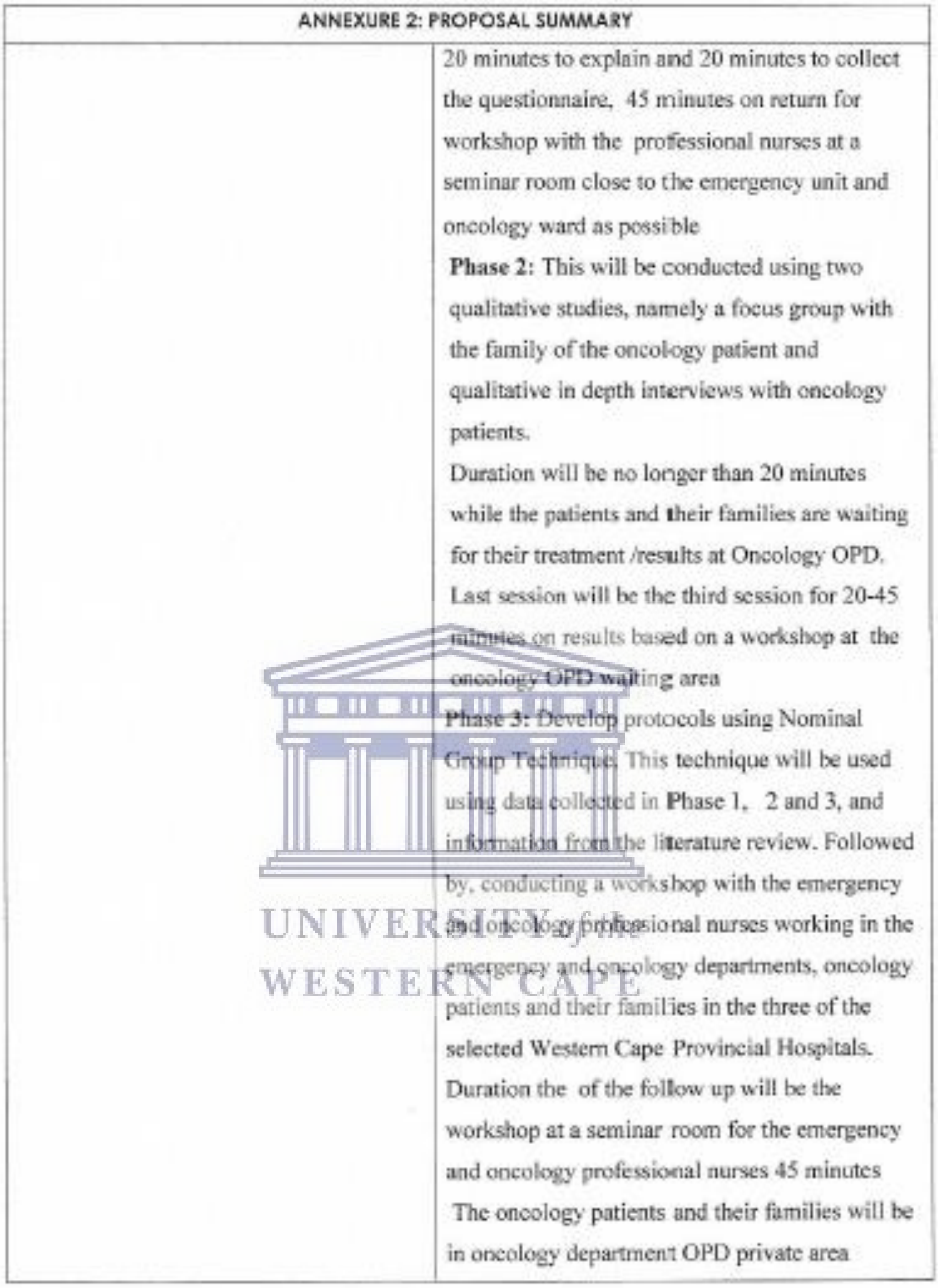
PO Box 2060, Cape Town, 8000
www.westerncape.gov.za



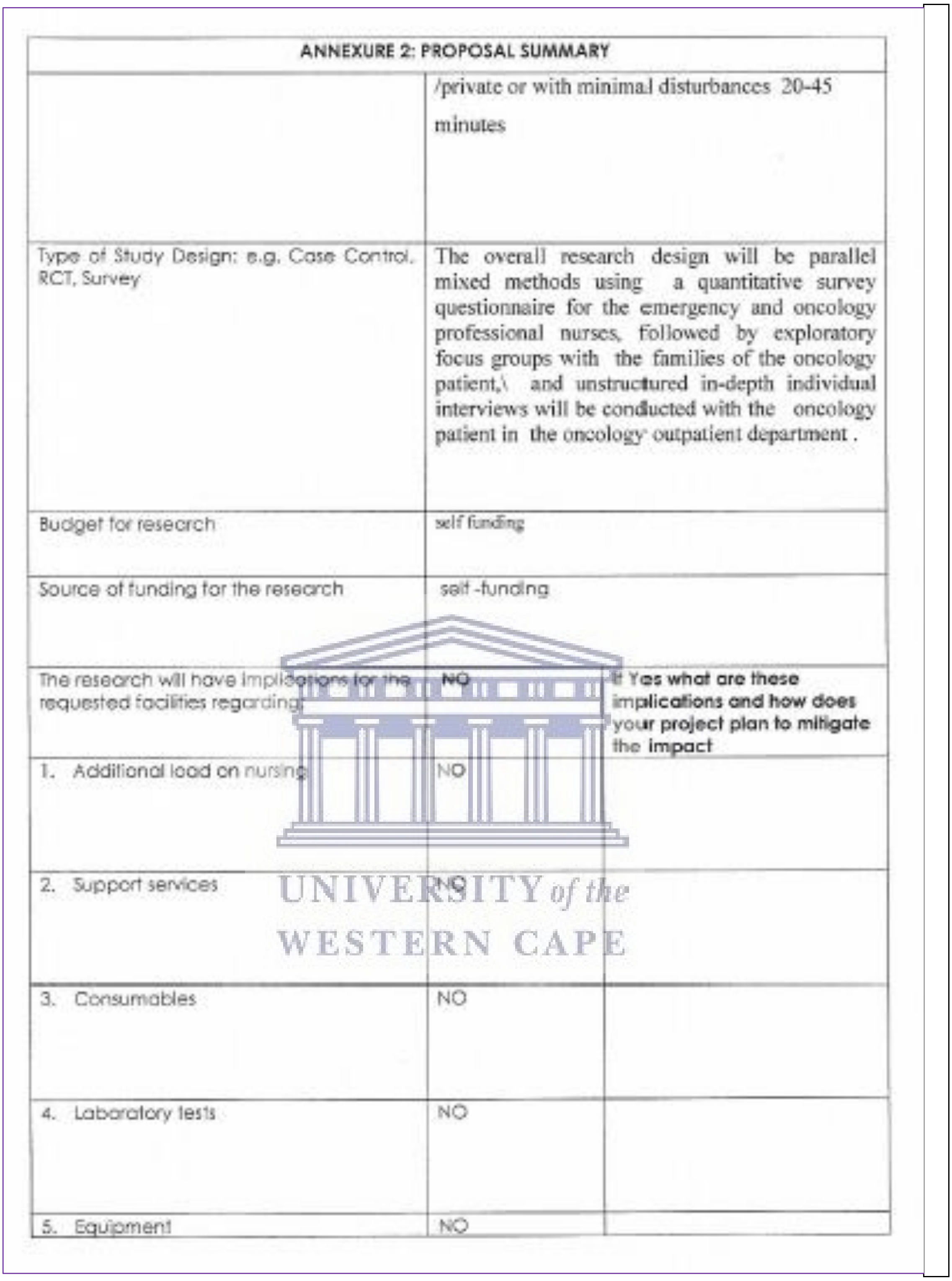
ANNEXURE 2: PROPOSAL SUMMARY	
Western Cape Government Health facilities where research will be done (please list the name of the facility under appropriate category)	**Tertiary Hospitals:** 1. TYGERBERG HOSPITAL 2. VICTORIA HOSPITAL 3. GROOTE SCHUUR HOSPITAL **District Hospitals:** **Community Health Centres:** **Clinics:**
Other facilities within Western Cape Government Health where research wil be done (please specify)	**Psychiatric Hospitals:** **TB Hospitals:** **Other:** Databases:
Research title	THE DEVELOPMENT OF PALLIATIVE CARE PROTOCOLS FOR EMERGENCY AND PROFESSIONAL ONCOLOGY NURSES IN THE GOVERNMENT HOSPITALS OF THE WESTERN CAPE
Research aim	The overall aim of the study is to develop applied palliative care protocols for emergency and oncology professional nurses to provide best practice palliative care nursing for oncology patients who may present at three of the Western Cape Provincial Hospitals.
Research objectives	To investigate the knowledge, attitudes and



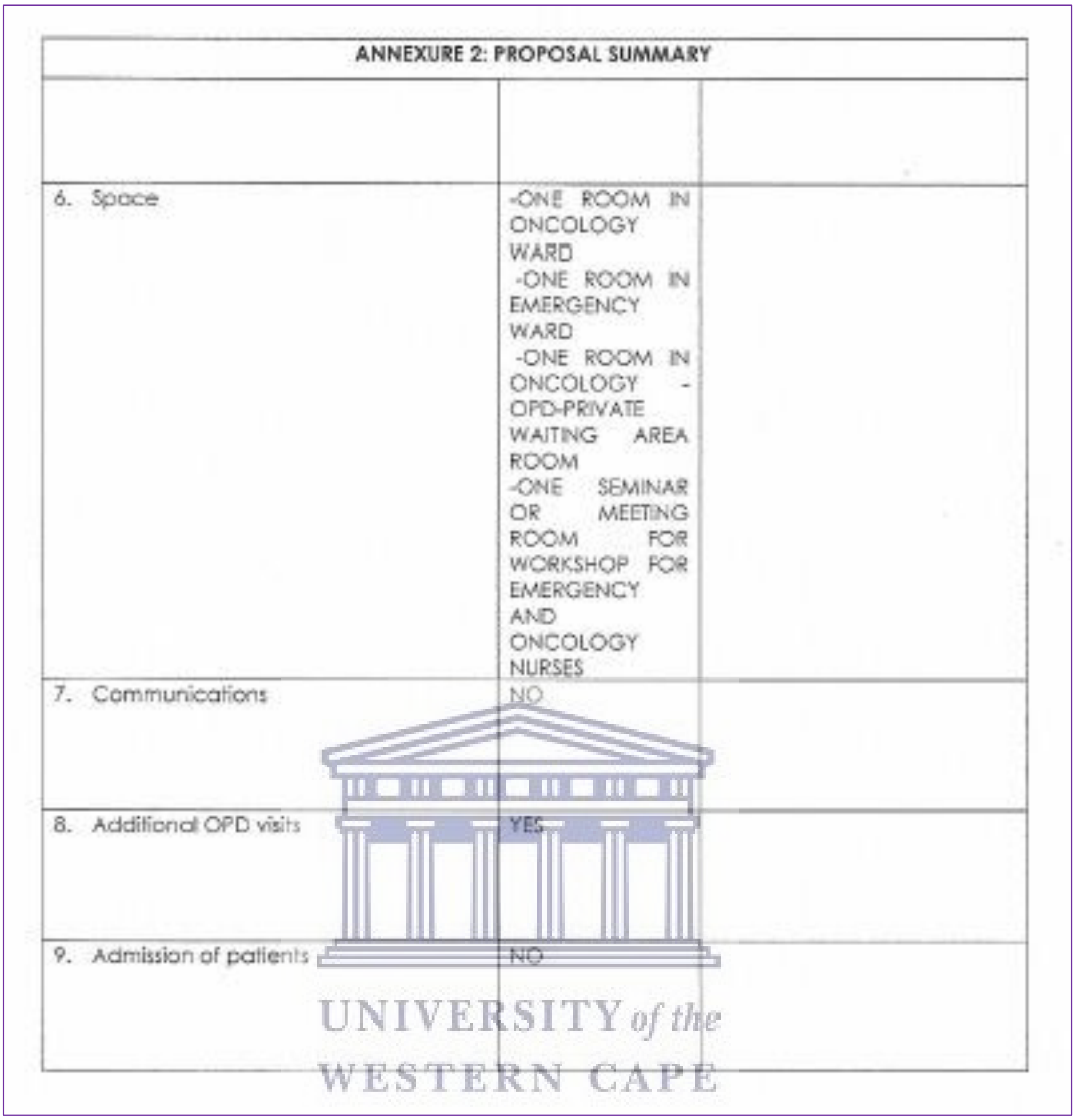
ANNEXURE 2: PROPOSAL SUMMARY	
	practices of the emergency and oncology professional nurses regarding palliative care nursing practices/procedures for oncology patients in three of the Western Cape Provincial Hospitals. To explore the perceptions and experiences of recipients of care (oncology patients and their families) regarding the delivery of palliative care in three of the Western Cape Provincial Hospitals. To develop palliative care protocols for emergency and oncology professional nurses to ensure high quality care for oncology patients in three of the highlighted Western Cape Provincial Hospitals.
Key Words	Death anxiety Emergency unit Family member; Oncology environment Oncology experience; Palliative care; Protocol; Professional Nurse
Brief description of methodology (please specify estimated sample size and duration of contact with each participant e.g. interview length, clinical exams)	The phases 1-3 of the proposal are set out below: not more than five participants per phase **Phase 1:** One study will be a quantitative survey using questionnaires and palliative quiz for the emergency and oncology professional nurses. Duration of contact at each of the three hospitals



ANNEXURE 2: PROPOSAL SUMMARY	
	20 minutes to explain and 20 minutes to collect the questionnaire, 45 minutes on return for workshop with the professional nurses at a seminar room close to the emergency unit and oncology ward as possible **Phase 2:** This will be conducted using two qualitative studies, namely a focus group with the family of the oncology patient and qualitative in depth interviews with oncology patients. Duration will be no longer than 20 minutes while the patients and their families are waiting for their treatment /results at Oncology OPD. Last session will be the third session for 20-45 minutes on results based on a workshop at the oncology OPD waiting area **Phase 3:** Develop protocols using Nominal Group Technique. This technique will be used using data collected in Phase 1, 2 and 3, and information from the literature review. Followed by, conducting a workshop with the emergency and oncology professional nurses working in the emergency and oncology departments, oncology patients and their families in the three of the selected Western Cape Provincial Hospitals. Duration the of the follow up will be the workshop at a seminar room for the emergency and oncology professional nurses 45 minutes The oncology patients and their families will be in oncology department OPD private area

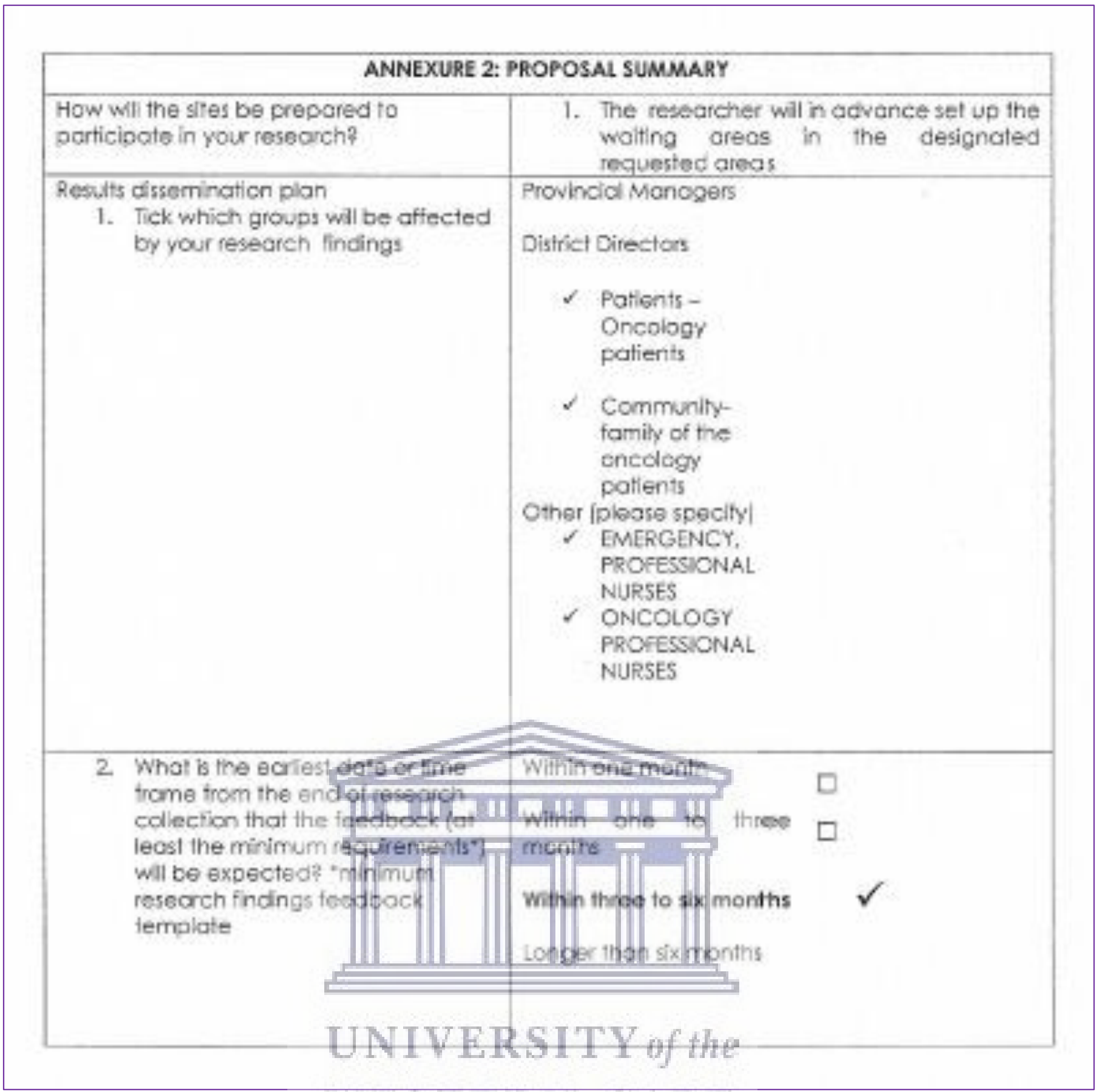


ANNEXURE 2: PROPOSAL SUMMARY		
	/private or with minimal disturbances 20-45 minutes	
Type of Study Design: e.g. Case Control, RCT, Survey	The overall research design will be parallel mixed methods using a quantitative survey questionnaire for the emergency and oncology professional nurses, followed by exploratory focus groups with the families of the oncology patient,\ and unstructured in-depth individual interviews will be conducted with the oncology patient in the oncology outpatient department .	
Budget for research	self funding	
Source of funding for the research	self -funding	
The research will have implications for the requested facilities regarding:	**NO**	**If Yes what are these implications and how does your project plan to mitigate the impact**
1. Additional load on nursing	NO	
2. Support services	NO	
3. Consumables	NO	
4. Laboratory tests	NO	
5. Equipment	NO	



ANNEXURE 2: PROPOSAL SUMMARY

6. Space	-ONE ROOM IN ONCOLOGY WARD -ONE ROOM IN EMERGENCY WARD -ONE ROOM IN ONCOLOGY - OPD-PRIVATE WAITING AREA ROOM -ONE SEMINAR OR MEETING ROOM FOR WORKSHOP FOR EMERGENCY AND ONCOLOGY NURSES	
7. Communications	NO	
8. Additional OPD visits	YES	
9. Admission of patients	NO	



ANNEXURE 2: PROPOSAL SUMMARY	
How will the sites be prepared to participate in your research?	1. The researcher will in advance set up the waiting areas in the designated requested areas
Results dissemination plan 1. Tick which groups will be affected by your research findings	Provincial Managers District Directors ✓ Patients – Oncology patients ✓ Community- family of the oncology patients Other (please specify) ✓ EMERGENCY, PROFESSIONAL NURSES ✓ ONCOLOGY PROFESSIONAL NURSES
2. What is the earliest date or time frame from the end of research collection that the feedback (at least the minimum requirements*) will be expected? *minimum research findings feedback template	Within one month ☐ Within one to three months ☐ **Within three to six months** ✓ Longer than six months

APPENDIX G

INFORMATION FOR THE ONCOLOGY PATIENT

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2271 Fax: 27 21-959 2679
E-mail: 3369398@myuwc.ac.za

APPENDIX: INFORMATION FOR THE ONCOLOGY PATIENT

Project Title: The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape

What is this study about?

This is a research project being conducted by Christine February at the University of the Western Cape. I wish to develop palliative care protocols for the professional Emergency and Oncology Professional Nurse in the government hospitals of the Western Cape. I am inviting you to participate in this research project because you are best suited to describe your expectations with regard to the development of palliative care protocols for Emergency and Oncology Nurses in the government hospitals of the Western Cape.

Would my participation in this study be kept confidential?

I will do our best to keep your personal information confidential. To help protect your confidentiality, we will use identification codes only on data forms, and will use password-protected computer files. Not all the information will be permissible to anyone and I will never mention your name in my records. Your identity will be protected to the maximum extent possible when I write a report or article about this research project.

What are the benefits of this research?

The benefit will be the provision of palliative care protocols within the Provincial health sector that is affordable to all patients with life-limiting illness and for seeing that it is being provided as quality care at the best cost-effective manner providing, adequate trained staff to deliver quality palliative care.

Do I have to be in this research and may I stop at any time?

Your participation in this research is voluntary. There is no risk to you for not participating other than use of your time. You may decide to stop participating. If you decide not to participate in this study or if you withdraw at any time, you will not be penalised or victimised. The researcher will ensure the Oncology Patient as participant of complete confidentiality and they should feel completely free to express their true feelings and opinions without fear of disapproval from the interviewer. A counsellor/psychologist will be made available for the Oncology Patient if needed. Rapport will correlate highly with understanding in unstructured interviews.

What if I have questions?

This research is being conducted by Christine February at the Directorate of the Western Cape College of Nursing. If you have any questions about the research study, please contact Christine February at: Western Cape College of Nursing, Klipfontein Road, Surrey Estate, Athlone, 7764. Telephone Number during office hours: 021 6841292/1204 or after hours: at 082 531 5909 email address: 3369398@myuwc.ac.za. Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please ask the researcher or contact

University of the Western Cape.
Dr S Arunachallam
School of Nursing
Faculty of Community and Health Sciences,
Private Bag X17, Bellville, 7535.
Tel: (021) 959 2523
Fax: (021) 959-2679;
Email: sarunachallam@uwc.ac.za

APPENDIX H

CONSENT FORM FOR THE ONCOLOGY PATIENT

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2271 Fax: 27 21-959 2679
E-mail: 3369398@myuwc.ac.za

APPENDIX: CONSENT FORM FOR THE ONCOLOGY PATIENT

Project Title: The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. The researcher will ensure the Oncology Patient as participant of complete confidentiality and feel completely free to express their true feelings and opinions without fear of disapproval from the interviewer. If the patient is not feeling well on that day, the researcher will re schedule the interview to date when the patient is feeling better. The researcher will ensure a psychologist or psychiatrist is available for any emotional or psychological support that may be needed by the patient during any time of the interview pre and post interview emotional and psychological support will be readily available.

Participant's name: ……………………………… **Participant's signature:** …………………………………

Date: ………………………………

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator.

University of the Western Cape
School of Nursing
Dr S. Arunachallam
Faculty of Community and Health Sciences
Private Bag X17
Bellville 7535
Tel: (021) 959-2523
Fax: (021) 959-2679

APPENDIX I

INTERVIEW SCHEDULE FOR THE ONCOLOGY PATIENT

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2271 Fax: 27 21-959 2679
E-mail: 3369398@myuwc.ac.za

APPENDIX: INTERVIEW SCHEDULE FOR THE ONCOLOGY PATIENT

Project Title: The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape

Hospital: ……………………………………
Age: …………………………………………
Gender: ……………………………………..
Diagnosis: …………………………………...

1. What has been your experience, regarding the delivery of current palliative care practices in this hospital?
2. Have you been admitted through the Emergency Department? Please tell me about your experience.
3. Have you been admitted to the Oncology Wards? Please tell me about your experience.
4. Please tell me about your experience in Out-Patient Department.
5. During the hospital stay, tell me about your experience of the staff
    a. Responsiveness and approachability of staff
    b. Willingness of staff to listen to you?
    c. Explaining issues in a way you could understand.
6. What do you feel could be improved in the delivery of your nursing care?
7. What could be improved about the discharge procedure?
    a. Sufficient information
    b. Communication
8. Have you contacted the hospital for support whilst at home? Tell me about your experience
    a. Support
    b. Concern?

APPENDIX J

INFORMATION FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2271 Fax: 27 21-959 2679
E-mail: 3369398@myuwc.ac.za

APPENDIX: INFORMATION FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

Project Title: **The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape**

What is this study about?

This is a research project being conducted by Christine February at the University of the Western Cape. I wish to develop palliative care protocols for Emergency and Oncology Nurses in the government hospitals of the Western Cape. I am inviting you to participate in this research project because you are best suited to describe your expectations with regard to the development of palliative care protocol for Emergency and Oncology Nurses in the government hospitals of the Western Cape.

Would my participation in this study be kept confidential?

I will do our best to keep your personal information confidential. To help protect your confidentiality, we will use identification codes only on data forms, and will use password-protected computer files. Not all the information will be permissible to anyone and I will never mention your name in my records. Your identity will be protected to the maximum extent possible when I write a report or article about this research project.

What are the benefits of this research?

The benefit will be the provision of palliative care protocols within the Provincial health sector that is affordable to all patients with life-limiting illness and for seeing that it is being provided as quality care at the best cost-effective manner providing, adequate trained staff to deliver quality palliative care.

Do I have to be in this research and may I stop at any time?

Your participation in this research is voluntary. There is no risk to you for not participating other than use of your time. You may decide to stop participating. If you decide not to participate in this study or if you withdraw at any time, you will not be penalised or victimised.

What if I have questions?

This research is being conducted by Christine February at the Directorate of the Western Cape College of Nursing. If you have any questions about the research study, please contact Christine February at Western Cape College of Nursing, Klipfontein Road, Surrey Estate, Athlone, 7764. Telephone Number during office hours: 021 6841292/1204 or after hours: at 082 531 5909 email address: 3369398@myuwc.ac.za if you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please ask the researcher or contact.

University of the Western Cape
School of Nursing
Dr S. Arunachallam
Faculty of Community and Health Sciences
Private Bag X17
Bellville 7535
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APPENDIX K

CONSENT FORM FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

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APPENDIX: CONSENT FORM FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

Project Title: **The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape**

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name: ……………………………… **Participant's signature:** …………………………………

Date: ………………………………

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator.

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APPENDIX L

QUESTIONNAIRE FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

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APPENDIX: QUESTIONNAIRE FOR THE PROFESSIONAL EMERGENCY AND ONCOLOGY NURSE

Project Title: **The development of palliative care protocols for professional emergency and the oncology nurse in the government hospitals of the Western Cape**

QUESTIONNAIRE NUMBER: _____

HOSPITAL: ______________________

GENDER:

☐ Male^1

☐ Female^2

AGE: _________

Answer all the questions by marking with an x in the box or a written answer

1. Which department do you work in? _____________________

☐ Trauma^1

☐ Oncology Ward^2

☐Oncology OPD^3

2. What is your professional rank? _________________________

☐Registered Oncology Nurse^1

☐Registered Emergency Nurse^2

☐Registered Nurse^3

3 How much oncology/emergency experience have you in years. _______

4. Have you received trauma/oncology training/in service in the last 12 months?

☐ **Yes**^{2}

☐ **No**^{1}

5. Rate the integration and referral processes in your hospital.

Department	**Good**	**Could be improved**	**Poor**
ED and Ward			
ED and OPD			
Ward and OPD			

7. Does your hospital have an MOU between ED and the oncology services?

☐ **Yes**^{2}

☐ **No**^{1}

Please answer True or False or Do Not Know to each of the following questions/statements.

Item	**True**	**False**	**Do Not Know**
8. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.			
9. Morphine is the standard used to compare the analgesic effect of other opioids.			
10. The extent of the disease determines the method of pain treatment.			
11. Adjuvant therapies are important in managing pain.			
12. It is crucial for family members to remain at the bedside until death occurs.			
13. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.			
14. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.			
15. Individuals who are taking opioids should also follow a bowel regime.			
16. The provision of palliative care requires emotional detachment.			
17. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment for severe dyspnoea.			
18. Men generally reconcile their grief more quickly than women.			
19. The philosophy of palliative care is compatible with that of aggressive treatment.			

20. The use of placebos is appropriate in the treatment of some types of pain.			
21. In high doses, codeine causes more nausea and vomiting than morphine.			
22. Suffering and physical pain are synonymous.			
23. Demerol is not an effective analgesic in the control of chronic pain.			
24. The accumulation of losses renders burnout inevitable for those who seek work in palliative care.			
25. Manifestations of chronic pain are different from those of acute pain.			
26. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.			
27. The pain threshold is lowered by anxiety or fatigue.			

Please rate your level of familiarity and your use of the following Palliative Care Guidelines

5 Very familiar, 4 Familiar, 3 Not so familiar, 2 Barely familiar 1 Not familiar

5 Use all the time; 4 Use most of the time, 3 Use sometimes; 2 Use seldom; 1 Never

	Familiar (a)						Use (b)				
Item	**1**	**2**	**3**	**4**	**5**		**1**	**2**	**3**	**4**	**5**
28. Section 56(A) of the Nursing Act to allow palliative care nurses to deliver palliative drugs											
29. Prognosticating disease and death											
30. Hospice Palliative Care Association Clinical Guidelines											
31. Management of Pain											
32. Management of Respiratory Symptoms											
33. Management of Gastrointestinal Symptoms											
34. Management of Neurological psychiatric symptoms											
35. Management of Constitutional symptoms of anorexia, asthenia, cachexia and fever and sweating											
36. Management of Infective Symptoms											
37. Management of Urinary Symptoms											
38. Pressure Care and Wound Care											
39. Patients in the terminal phase											
40. Palliative Care Emergencies											

41. Communication											
42. Breaking bad news and building hope											
43. Psychosocial assessment											
44. Psychosocial care											
45. Loss Grief and Bereavement											
46. Culture and Spirituality in Palliative care											
47. Psychosocial emergencies e.g. suicide											
48. Social Emergencies e.g. Financial issues											

Mark each answer on the sheet that corresponds with your personal feelings about the attitudes or situations presented. Please respond to all the statements.

Indicate the following on a scale of 0-5:

Strongly agree 5; Agree 4; Mildly agree 3; Disagree 2; Totally disagree 1; Not important 0

Item	**5**	**4**	**3**	**2**	**1**	**0**
49. Giving nursing care to the dying person is a worthwhile learning experience.						
50. Death is not the worst thing that can happen to a person.						
51. I would be uncomfortable talking about impending death with the dying person.						
52. Nursing care for the patient's family should continue throughout the period of grief and bereavement.						
53. I would not want to be assigned to care for a dying person.						
54. The nurse should not be the one to talk about death with the dying person.						
55. The length of time required to give nursing care to a dying person would frustrate me.						
56. I would be upset when the dying person I was caring for gave up hope of getting better.						
57. It is difficult to form a close relationship with the family of a dying person.						
58. There are times when the dying person welcomes death.						
59. When a patient asks, "Nurse is I dying?" I think it is best to change the subject to something more cheerful.						
60. The family should be involved in the physical care of the dying person.						
61. I would hope the person I am caring for dies when I am not present.						

62. I am afraid to become friends with a dying patient.						
63. I would feel like running away when the person actually died.						
64. Families need emotional support to accept the behaviour changes of the dying person.						
65. Families should be concerned about helping their dying member make the best of his/her remaining life.						
66. The dying person should not be allowed to make decisions about his/her physical care.						
67. Families should maintain as normal an environment as possible for their dying member.						
68. It is beneficial for the dying person to verbalise his/her feelings.						
69. Nursing care should extend to the family of the dying person.						
70. Nurses should permit dying people to have flexible visiting schedules.						
71. The dying person and his/her family should be in the charge decision makers.						
72. Addiction to pain-relieving medication should not be a nursing concern when dealing.						
73. I would be uncomfortable if I entered the room of a terminally ill person and found him/her dying.						
74. Dying people should be given honest answers about their conditions.						
75. Educating families about death and dying is not a nursing responsibility.						

Thank you

APPENDIX M

CONFIRMATION BY LANGUAGE EDITOR

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23 July 2018

To Whom It May Concern

This serves to confirm that I have edited the language, spelling, grammar and style of the PhD dissertation by **Christine February**, entitled: "**The development of palliative care protocols for Emergency and Oncology Nurses in the government hospitals of the Western Cape**" The manuscript was also professionally typeset by me.

Sincerely Yours

Dip. Freelance Journalism, Dip. Creative Writing, MSc (Medicine), PhD