

**AN ASSESSMENT OF THE INTEGRATION OF PALLIATIVE CARE IN THE  
CARING OF CANCER PATIENTS IN SELECTED ONCOLOGY CLINICS IN  
THE ETHEKWINI DISTRICT IN KWAZULU-NATAL**

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Masters of Technology in Nursing in the Faculty of Health Sciences at the  
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## Declaration

This is to certify that this work is entirely my own and not of any other person, unless explicitly acknowledged (including citation of published and unpublished sources). This work has not previously been submitted in any form to the Durban University of Technology or to any other institution for assessment or for any other purpose.

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Signature of student

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## **Abstract**

### **Background**

Palliative care research in South Africa is at an early stage and there is an increasing need to develop a body of evidence that is relevant to South African conditions. One of the biggest challenges that palliative care in Africa faces is the projected increase in the number of cancer patients in the developing world by 2050, many of whom will need palliative care. There is a concern at present about the integration of oncology and palliative care services in South Africa and whether or not cancer patients are able to access quality palliative care. Palliative care plays an important role in improving quality of life for people and family members affected by life-threatening illness. It pursues its goal by relieving pain and other distressing symptoms in cancer patients and giving psychosocial support to patients and their families. It should begin at diagnosis and continue throughout treatment, follow-up care, and at the end of life in addition to the cancer treatment which is given

### **Aim of the study**

The aim of this study was to assess the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni district in KZN.

### **Methodology**

A qualitative, explorative, descriptive and contextual research design was used to guide this study. The study was participative in nature and employed a focus group methodology. The participants in this study were professional nurses who were working at the selected sites in the public urban oncology clinics for more than three months. Two focus groups were conducted within one month of each other at selected oncology sites with participation from 16 oncology nurses.

## **Findings**

Findings indicated that most participants understood palliative care as end of life care when a patient is beyond curative treatment and that it is often the doctor who determines eligibility. Participants also perceived palliative care in terms of different types of medical treatment. The findings indicated nurses only contacted hospices when the patient was at the last stage of their illness, were often not aware of all the hospices in the area, and acknowledged that communication between the oncology clinics and hospices was not good. Some nurses believed that palliative care is also provided in the oncology clinic and that it is not only the hospices that provide palliative care. Only one oncology nurse who participated in the study mentioned that she is trained in palliative care, but they all showed interest in becoming more knowledgeable in this area and improving relationships between oncology clinics and the palliative care team/hospices.

## **Dedication**

The study is dedicated to my dearest sister, Ms Busisiwe Shamase, who died of breast cancer in terrible pain and who did not have access to palliative care.

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## Acronyms

<b>Acronym</b>	<b>Full word</b>
ASCO	American Society of Clinical Oncology
CBOs	Community-based organizations
CHBC	Community home-based care
CST	The cancer Support Team
FBOs	Faith Based Organisations
FGDs	Focus Group Discussions
HPCA	Hospice Palliative Care Association
ICHC	Integrated Community-based Home Care
ICN	International Council of Nursing
IPU	In-patient units
KZN	KwaZulu-Natal
NNPC	Neighbourhood Network in Palliative Care
NGO	Non-Government Organisation
PLHA	People living with HIV/AIDS
PN	Professional nurse
PHC	Primary Health Care
WHO	World Health Organisation

## **CHAPTER 1**

### **OVERVIEW OF THE STUDY**

#### **1.1 INTRODUCTION**

This research project assesses the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni district in KZN. Ultimately the aim of the research is to ensure that cancer patients in need of palliative care are appropriately supported and their quality of life is optimised. Chapter 1 provides the overview of the study in a form of a problem statement, outlines the definitions and principles of palliative care along with the development of the modern global hospice/palliative care movement. It further looks at palliative care for oncology patients, the need for oncology nurses to be skilled in palliative care and the referral of cancer patients to palliative care. The purpose of the study, objectives and the definition of terms are outlined. Chapter 2 follows with a more focused literature review on what is currently known about the integration of palliative care in oncology clinics, contemporary models of palliative care in South Africa, the role of the oncology nurse in palliative care and the referral of cancer patients for palliative care as part of a continuation of care. It seeks to highlight the current research gaps in this area, in particular reference to South Africa. The methodology behind this study is revealed in Chapter 3, leading onto the presentation of the findings in Chapter 4. A critical discussion of the findings, along with the study's limitations, is presented in Chapter 5 before setting out some concluding remarks and making specific recommendations for policy and practice.

#### **1.2 PROBLEM STATEMENT**

Stjernsward (2007: 514) reports that most countries do not have palliative care policies, pain policies, integrated palliative care services or hospices that include palliative care as a human right for the caring of cancer patients, AIDS care and elderly care. The American Cancer Society (2008: 1) predicted that worldwide the number of cancer

cases will double to 21.4 million by 2030, and nearly two thirds of all diagnoses will occur in low- and middle-income countries and 13.2 million cancer deaths simply due to the growth and aging of the population.

According to The World Health Organisation's own figures, as a result of ageing, population growth alongside increasing adoption of cancer causing behaviour in developing countries, incidences of cancer will more than double to an estimated 24 million new cancers per year by 2050 (WHO, 2011). Stjernsward (2007: 515) further states that an estimated 60% of cancer victims worldwide will have major pain, and worldwide two thirds will not be cured. He further states that 35 million people worldwide presently are experiencing pain and suffering when dying, without access to palliative care. Globally, the establishment of a National Cancer Control Programme provides the means of achieving control even with limited resources. A cancer control programme includes the integrated activities of prevention and health promotion, early detection, treatment, palliative care and monitoring (WHO, 2011).

Africa itself has a population of 965 million people. Each year, 650 000 people die from cancer (Parkin et al., 2008). According to these authors, the lifetime risk of females dying from cancer in Africa is double the risk of those living in the developed countries (Parkin et al., 2008). In South Africa the 2000-2001 National Cancer Registry shows that male have a lifetime risk of 1 in 6 of getting cancer and women have a lifetime risk of 1 in 8 of getting cancer. The problem in South Africa is that National Cancer Registry was last reported to CANSA in 2000-2001 and one cannot be sure if the cancer statistics are correct or up to date. The report (WHO 2011) estimates that 48,800 people died of cancer in South Africa in 2008 while HPCA cared for 36,600 patients that year of which 16% had cancer, that is, 5,856 patients received palliative care (HPCA Evaluation report 2011). Also a report by Insideout (2011) states that that the population who might benefit from palliative care is underrepresented based upon

estimates of cancer deaths in South Africa. Healthcare professionals and people who could benefit from palliative care view palliative care as care of the dying only.

### **1.3 PURPOSE OF THE STUDY**

The purpose of this study was to assess the integration of palliative care in the caring of cancer patients in two selected oncology clinics in the eThekweni district in KZN.

### **1.4 OBJECTIVES OF THE STUDY**

The objectives of the study were to:

- Describe professional nurses' understanding of palliative care
- Describe the referral process to hospice palliative care
- Determine the extent to which oncology nurse provide palliative care

### **1.5 DEFINITION OF TERMS**

#### **1.5.1 Palliative care definition, principles, norms and standards**

Palliative care is an “approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief from suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2011).

As the WHO definition of palliative care stresses its importance to patients not responsive to curative therapy, it might be interpreted as restricting palliative care to the last stages of care. Today there is wide recognition that the principles of palliative care should be applied as early as possible in the course of any life threatening illness. This



change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier stage in the course of disease.

### **1.5.2 Principles of palliative care**

According to Green and Horne (2009) the following are the principles of palliative care:

- Quality of life: Service provide should not define the quality of life but it should be defined by the individual.
- Respectful and participatory: Patients and families have the right to make choices, use their cultural and personal values, confidentiality, and be treated with dignity.
- Holistic: To address diverse needs of patients and the family, interdisciplinay teams should be involved to attend to the emotional, spiritual and social aspects of care.
- Family centered: In the caring of palliative care patients the families should be involved in the care process, providing them with needed confidence, information, and skills to support their loved one.
- Sustainable: For the sustainability of palliative care it should be integrated into the local system, community, and environment, to ensure the benefit for all.
- Integrated palliative care services are provided through existing health, psychosocial and spiritual support services.

### **1.5.3 Levels of palliative care within norms and standards**

According to Radbruch and Payne (2010: 285) The Council of Europe recommends that all professionals working in healthcare should be confident with the basic palliative care

principles and able to put them into practice and palliative care should be provided in two levels:

#### 1.5.3.1 Palliative care approach

It is a way to integrate palliative care methods and procedures to general practitioners and staff in general hospitals, as well as for nursing services and for nursing home staff. To achieve the palliative care approach palliative care has to be included in the curricula for medical, nursing and other related professionals' basic education. This includes pharmacological and non-pharmacological measures for symptom control and also communication with patient and family as well as with other healthcare palliative care.

#### 1.5.3.2 Specialist palliative care

It applies to a team of trained physicians, nurses, social workers, chaplains and others whose expertise is required to optimise quality of life for those with a life-threatening illness. These services care for patients with difficult needs and therefore require a higher level of education, staff and other resources. All patients with progressive incurable diseases should have access to specialist palliative care services. It requires a team approach, combining a multiprofessional team with an interdisciplinary mode of work.

#### 1.5.3.3 General palliative care

Radbruch and Payne (2010: 285) further state that “this two-step ladder of care levels can be extended to three steps, with a palliative care approach, general palliative care and specialist palliative care”. General palliative care is provided by primary care professionals who are involved more often in palliative care, such as oncologists or geriatric specialists, but do not provide palliative care as the main focus of their work, still may have acquired special education and training in palliative care and may provide additional expertise and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge.

#### 1.5.3.4 Centres of excellence

The ladder can also be extended to a fourth level, that of centres of excellence. Centres of excellence should provide specialist palliative care in a wide variety of settings, including in- and outpatient care, home care and consultation services, and should provide academic facilities for research and education. It should act as a focus for education, research and dissemination, developing standards and new methods (Radbruch and Payne, 2010: 285).

#### **1.5.4 Cancer**

Cancer is a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can then invade adjoining parts of the body and spread to other organs. This process is referred to as metastasis. Metastases are the major cause of death from cancer (WHO, 2011).

#### **1.5.5 Oncology**

Oncology is a “branch of medicine that deals with tumours, including the study of their development, diagnosis, treatment, and prevention” (WHO 2011). For the purpose of this study, the oncology clinic is the department within the hospital where cancer patients go for treatment and check-ups and are seen by the oncology interdisciplinary team.

#### **1.5.6 Professional nurse**

The South African Nursing Council (2005) defines a professional nurse as a person who is qualified and competent to independently practise comprehensive nursing in the

manner and to the level prescribed, and who is capable of assuming responsibility and accountability for such practice. For the purpose of this study a professional nurse means a person who is qualified and competent to independently practise comprehensive nursing in the manner and to the level prescribed, and who is capable of assuming responsibility and accountability for such practice in the oncology clinic.

## **1.6 DEVELOPMENT OF PALLIATIVE CARE**

According to DeSpelder and Strickland (2011: 192) Cecily Saunders, who is widely regarded as the founder of the modern hospice movement, emphasized the importance of palliative care in modern medicine. She developed a systematic approach to pain control in terminally ill patients and concentrated on the holistic care that includes emotional, social and spiritual care. She started to teach other people what she knew about holistic care. Traditionally, hospices were sanctuaries provided by religious orders for the dying poor. They offered food, clothing, shelter and medical care. Saunders began working at the Roman Catholic St Joseph's Hospice in east London where she researched pain control. She decided to set up her own hospice which focused on cancer patients. DeSpelder and Strickland (2011: 192) further describe the establishment of St Christopher's hospice was established in 1967. This is the world's first purpose-built hospice. The hospice was founded on the principles of combining teaching and clinical research, expert pain and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of its patients and those of their family and friends. Since then, the hospice movement in the UK has had a considerable impact on the care of dying people at home and abroad.

Wright et al. (2006: 28) in their study evaluating international palliative care services found that more than 150 countries were engaged in providing hospice-palliative care service or developing the framework within which such a service can be provided. The development is still patchy with palliative care approaching a measure of integration

with wider service providers in just 15% of the countries listed. Half of the 234 countries included in their study have established one or more hospice-palliative care services. According to the same study, in 78 (33%) countries, no palliative care activity can be identified. Still Doyle (2003: 149) commented on the remarkable development of palliative care which as a relatively new specialty, has become a global movement in growing and sharing its expertise with others be identified at all (Wright et al 2006: 19).

## **1.7 DEVELOPMENT OF PALLIATIVE CARE SERVICES IN SOUTH AFRICA AND KWAZULU-NATAL**

A lecture tour by Dame Cecily Saunders in 1979 facilitated the establishment of hospice programmes in South Africa and the early hospice programmes were based on the United Kingdom model. Wright et al. (2006: 29) further described how palliative care was established in South Africa towards the end of the 1970s in Johannesburg, Cape Town, Durban and Port Elizabeth. In 1988, 14 hospices came together to form a national association called the Hospice Association of South Africa (HASA). In 2006 about 120 member organisations had become members the Association of South Africa. In 2003 the name of this association was changed to the Hospice Palliative Care Association (HPCA). Prior to 1988, hospices dealt predominantly with oncology patients but with the impact of the HIV/AIDS pandemic. The hospice programmes changed the way care was being delivered and increased access. HPCA member hospices realised that they needed to partner with other organisations to provide palliative care and would not on their own have the capacity to meet the needs of patients who needed palliative care (Defilippi and Cameron 2007: 554). The HPCA adopted the Integrated Community-based Home Care Model (ICHC) in 2001-2002 and developed the first phase of a mentorship programme to be implemented in 28 HPCA member hospices (Defilippi and Cameron 2007: 553).

A report by Insideout (2011) states that HPCA has 200 member services sites which operate in all the provinces of South Africa. Many of these organisations have branches

which provide palliative care services in local settings. Service types include: in-patient care; home care; day care; clinics/drop-in centres; hospital support teams; education and training; patient support groups; bereavement care; foster parent support groups; orphan support groups and hospice care for the homeless. Hospices in South Africa are non-governmental organizations and are registered charities. A report by Insideout (2011) further mentions that the South African hospices rely on community support for finances and staffing, and would not exist without their strong and dedicated volunteer corps. The majority of South African hospices also rely on professional volunteers; for example, doctors, nurses, social workers, and spiritual workers, who often provide their services in a volunteer capacity. Between July 2010 and July 2011 HPCA records indicate that 94,585 patients were cared for in South Africa of whom 79% had HIV and AIDS, 17% chronic diseases and 5% cancer. During that time period, most of the referrals originated from primary healthcare (PHC) clinics, hospitals, and family and friends (Insideout, 2011).

Wright and Clark (2006:35) reported that palliative care in KZN was started by Greta Schoeman caring for cancer patients in her home. In 1982 the Hospice Association of KwaZulu-Natal, under the chairmanship of Matron Lyall Cremer, held its Inaugural Meeting. Wright and Clark (2006: 35) also mentioned In June 1982 Greta Schoeman founded the Highway Hospice, which became the first branch of this Association. When interviewed on the 11<sup>th</sup> of August 2011, Konjore (HPCA Monitoring and Evaluation Manager) stated that KZN province has 18 member hospices and 12 affiliated members in HPCA and there are only 6 hospices in the province that have in-patient units. The total number of KZN patients cared for between July 2010 and July 2011 was 25,776. 80% of those patients had HIV/AIDS, 14% had chronic, advanced non-cancerous diseases, and 5% had cancer.

## **1.8 PALLIATIVE CARE FOR ONCOLOGY PATIENTS**

According to Osse et al. (2005:1) Palliative care is given in addition to cancer treatment and not all cancer patients can be cured regardless of the earlier diagnosis and improved of methods of treatment. The authors further state that the early diagnosis and improved of methods of treatment has the benefit for the patients to live for longer period of time and when there is no chance of cure, professional care focus is on quality of life.

Ferris et al (2010: 3052) recommend that palliative cancer care needs to be available to patients and families in all settings where they receive care, including outpatient clinics, acute and long-term care facilities, and private homes. By 2020, the United States and several other countries will have national cancer control plans that include palliative care as a routine part of comprehensive cancer care for all patients. The American Society of Clinical Oncology (ASCO) recommends changes in policy, drug availability, and education recognizing that palliative care should expand from end-of-life care and should integrate throughout the illness experience.

## **1.9 THE NEED FOR ONCOLOGY NURSES TO BE SKILLED IN PALLIATIVE**

Nurses spend quality time with patients and are well placed to impact on their care and the outcomes of that care. Oncology nurses in particular have a major role in supporting patients through their cancer journey. Patients with cancer often have a great symptom burden because of the nature of the disease and the consequences of treatments. Quinn (2008: 2), in linking the expanding role of oncology nurses to advances in cancer treatment, states that nurses have a key role to play in assessing the patient, in symptom management and education about cancer. The author argues that the challenge is to ensure that all nurses working in this area are well-educated, independent thinkers. There is an acknowledgment as well that the role can differ greatly across cultures and the importance of developing collaborative relationships

among oncology nurses across the globe.

### **1.10 REFERRALS OF CANCER PATIENTS TO PALLIATIVE CARE**

As previously stated, according to HPCA (2011), only a limited number of cancer patients are referred for palliative care and normally only for terminal care. This would suggest that palliative care is not well integrated into the healthcare system. Access is limited, and many healthcare professionals and lay people are unaware of its possible benefits. Healthcare professionals and the public in many countries, including South Africa, are still struggling with the commonly held view that palliative/hospice care equates to end-of-life care only. This erroneous view has a profound impact on referrals to these services. When interviewed on the 15 March 2011 Dr.Liz Gwyther, (Chief Executive Officer) stated that HPCA member hospices do not usually work in cancer centres and they wait for the patient to be transferred to them before starting to provide palliative care. The process of referrals to palliative care services is also affected by lack of education as in South Africa curricula at medical schools and in nursing schools' training programmes contain minimal formal courses on palliative care (Gwyther, 2008: 14).

### **1.11 CONCLUSION**

South Africa is one of four countries in Africa where palliative care services are considered to be approaching a measure of integration with mainstream service providers (Wright and Clark, 2006: 99). One of the characteristics of such a palliative care service includes a broad awareness of palliative care among health care professionals and local communities. HPCA report (2011) indicated that the population who might benefit from palliative care is underrepresented based upon estimates of cancer deaths in South Africa. In KZN alone, between July 2010 and July 2011, HPCA records also indicated that only 5% of patients seen by local palliative care services had a diagnosis of cancer. So there is a real concern that, in spite of this broad awareness



among health care professionals, in the area of oncology the integration of palliative care services is limited and cancer patients are not able to access the palliation they need to optimise their quality of life. Historically, nurses have played a significant role in the care of patients with cancer. There is a need for research and evidence based work that is relevant to African conditions. This study explores the role of oncology nurses in promoting access to quality palliative care.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 METHODS OF CONDUCTING LITERATURE SEARCH

A nexus search of the literature was conducted over a period of six months, using different scholarly search engines. The researcher followed a two-step process to do a literature search.

##### 2.1.1 Steps of conducting a literature search

*Step 1- Choosing the most appropriate databases:*

As a general rule, a thorough search should include Medline and at least 1 other database. Medline provides authoritative medical information on medicine, nursing, dentistry, health care and much, much more. It searches citations from more than 5,400 biomedical journals. Cinahl with full text is the world's most comprehensive source of full text and allied health journals, providing full text from more than 610 journals.

*Step 2- Focusing the search question*

It is important to plan a literature search in advance and to think about it in terms of the question being asked. This review was aimed at answering the following question: what are the knowledge and experiences among oncology nurses of the integration of oncology and palliative care? The search strategy included using obvious key words related to palliative care, end of life care combined with oncology or related terms, as well as nurses or related terms, in addition to other key words that reflect integration of services, e.g. service development.

In each database, a variation of the following search was used:

- Oncology and oncological care, or
- Palliative care and end of life care and terminal care, or
- Palliative nursing and hospice nursing, or
- Integration, or
- A combination of numbers 1 and 2 and 3 and 4

### *Result of initial search*

This initial search yielded a total of 109735 citations. The parameters of the search were refined to include the following conditions: Full text; dated between 2000 to present; involving humans; major headings including hospice and palliative nursing, palliative care, terminal care, hospice care, terminally ill patient and cancer patients. The subsequent search revealed 597 results. The World Wide Web including search engines such as Google Scholar was also searched for similar key words, producing a number of further papers and resources. The reference lists of key articles were scrutinized and this identified other relevant articles. In terms of trying to provide as complete an overview of available knowledge and resources, the following materials were included in addition to peer reviewed and non-peer reviewed journals; materials on the World Wide Web; unpublished materials, reports, training and information materials. Titles and in case of doubt, abstracts were assessed on suitability for inclusion based on the following criteria: The results of the database search and the Worldwide Wide Web search were then reviewed using the following criteria:

### *Inclusion Criteria*

- 2000 to present (this timeframe should cover current and ongoing themes in palliative care and oncology)
- Any papers or materials directly concerned with or related to palliative care and oncology, or palliative and hospice nursing, as well as oncology nursing.
- Any papers or materials focusing on other issues such as integration or service development in oncology and palliative care, especially in Africa.

### *Exclusion Criteria*

- Pre-2000
- Non-English language
- Articles from the field but not relevant to palliative care/end of life care and oncology.

## **2.2 BACKGROUND OF PALLIATIVE CARE**

This literature review seeks to look at what is currently known about the integration of oncology and palliative care along with the knowledge and understanding of oncology nurses in this area. It also reviews different models of delivering oncology and palliative care as well as the process of referring patients. It aims to summarize what has been written into conclusion points, identifying research gaps in the literature that will provide a justification for the study that follows. In considering the rationale for the review and the methodology employed, it would be worthwhile to introduce the reader to some international, regional and local issues in palliative care that influence and shape this research project.

According to Doyle (2003: 149), after some initial scepticism and suspicion, not only has it gained a professional respectability, there are now more governments embedding palliative care in their health care strategies and as evidenced by increased donations, “the public, the consumers as they are called in our modern market-driven world has taken it to their hearts (Doyle 2003: 149). However, he points out, palliative care has become synonymous with the affluent, developed countries in the West and any delight at its progress has to be tempered with the recognition that “nearly half of the world’s peoples have no access to it and their doctors no training in it” (Doyle, 2003: 150). Population ageing and the emerging needs for care of people living with serious chronic illnesses have also made palliative care become an important global public health issue (WHO 2004: 8). Many countries with established palliative care services are recognizing that some groups in society still do not have equitable access to palliative care, particularly those with non-malignant conditions. People living with different chronic illnesses often have similar needs, and with more evidence for the effectiveness of palliative care, the challenge ahead is for it to be offered more widely and integrated more broadly across health care services.

Traditionally, as noted in chapter one, palliative care has been offered most often to people suffering from cancer and normally in the context of end of life care. The concept of palliative care as an intervention that can be offered alongside potentially curative treatment, on the basis of need and not of diagnosis has still to take firm hold. However, Doyle (2003: 150) cautions against ‘missionaries’ of palliative care claiming a monopoly on caring, that “we ourselves want to be involved from the moment of diagnosis because we could give better care” (Doyle 2003: 151). Instead, he urges that the principles of palliative care are disseminated so that they are seen as integral to all care. In resource poor settings, this message becomes even more important.

Even definitions of palliative care are not universal and many different names have been used from terminal care, care of the dying, end of life care, hospice, palliative care, continuing care, to supportive care. To address this potential for confusion over definitions, The World Palliative Care Alliance (WPCA, 2009: 1) recommended that all governments should:

- Adopt the WHO definition of palliative care
- Integrate palliative care into their country's health care system
- Support and work in collaboration with the NGO sector in the delivery of palliative care.

Gwyther and Krakauer (2009) further stated that “the organization and provision of palliative care has to be adapted to the country, culture and context if the needs of the person requiring care and their family members are to be met”. It can be seen as a movement away from the notion that everything offered by the West, even palliative care, should be adopted without question. Indeed, Doyle (2003: 151) argues that palliative care in the West has much to learn from the developing world, such as working with limited resources and mobilizing the strengths of communities among other things. For example, in countries like South Africa, in response to the HIV/AIDS epidemic, the scope of palliative care has been expanded to include the provision of social and legal support that will also assist with poverty alleviation, as well as food security.

Countries like Uganda and South Africa have made sustained gains in providing palliative care through community based programmes and home based care. The first fully integrated public sector palliative care service was launched in South Africa's largest hospital in 2008. Broadly speaking, although this a good sign for the future development of palliative care services in South Africa, it has to be understood alongside the epidemiology of Cancer in Africa where 1 in 5 deaths is caused by the

disease, the lifetime risk of cancer is set to increase by 50-60% and the number of cases to rise from 600,000 to 2.4million (Parkin et al. cited in Selman et al. 2011: 2). Added to this is data from the HPCA report (2011) that suggests that only 5% of patients referred to their members have cancer. One of the drivers for this research project was a concern that this HPCA data reflects the different perceptions of palliative care held by health care professionals and people, a sizable minority of whom have perpetuated the view that palliative care is limited to care of the dying, resulting in referrals and access to palliative care being restricted for many people who could receive significant benefit from this care earlier in their illness. According to Harding et al. (2008: 304), a major barrier to the development of palliative care in the region is the lack of data to inform service provision as most research has focused on opioid availability and the physical aspects of care. This study into the knowledge and experiences among oncology nurses of the integration of oncology and palliative care is a timely attempt to provide data to inform service provision in this important area. The literature review that follows is an attempt to understand what is currently known about the subject and provide further justification for the study project.

### **2.3 PALLIATIVE CARE IN ONCOLOGY CLINICS**

The literature review confirmed that in the area of oncology and palliative care, most studies have been conducted in countries where palliative care is fully integrated, e.g. the UK and United States and there is a dearth of research that is local to Africa. Despite the fact that there is progress in cancer treatment, approximately half of cancer patients die and one third of cancer deaths happen within six months of their diagnoses (Hui et al., 2010: 1054). The authors highlight the fact that the American Society of Clinical Oncology has now taken a step further to support full integration of palliative care as a routine part of comprehensive cancer care in the United States by 2020. In fact, the literature search revealed many examples of articles that highlighted the universal support for this concept (Griffith et al., 2010: 171; Oncology Nurses Society: 2007:1097; Meier et al., 2008: 823; Schoefield et al., 2006: 397; Whedon 2001: 2).

In an editorial titled “The Terminally Ill: Dying for Palliative Medicine?” oncologist Declan Walsh described cancer research establishments as being in great denial about the need for palliative care (Walsh and Gordon (2001: 203). Whedon (2001: 2) remarks that doctors and nurses currently practice in a death dying culture that accepts a dichotomy of care more focused on quantity of life and treatment at all cost where many doctors, nurses, patients and their families experience conflict and turmoil agreeing an appropriate time to make a shift from one to the other. In outlining barriers to integrating palliative care into oncology settings, she also describes how some health care colleagues resisted the palliative care approach only endorsing a curative focus aimed at accommodating patients with episodic, short term fixable problems.

This discomfort is heightened by the prevailing “real world” of healthcare in America where, in a culture of health plans and insurance policies, the curative and palliative care approaches are seen as being mutually exclusive (Byock, 2000: 123). This has led to decisions about life prolonging treatments and palliative care being seen as an either or situation. Subsequently, comprehensive palliative care with its focus on managing symptoms, psychosocial support and assistance with decision-making, is only initiated after life-prolonging treatments are no longer available or have been rejected by the patient. Thus, the potential to improve the quality of life and ensure a smooth transition to end-of-life care is considerably reduced. In another qualitative study, family members who perceived that they were referred to hospice programmes too late reported more unmet needs, greater concerns and lower concerns (Teno et al., 2007: 122).

Given the trends toward aggressive and costly care near the end of life among patients with cancer Behl et al. (2010: 831), there is growing research evidence that the early introduction of palliative care lessens unnecessary and burdensome personal and societal costs. In an American study conducted by Temel et al. (2010: 733), 151 patients with newly diagnosed metastatic non–small-cell lung cancer were randomly assigned to receive either early palliative care integrated with standard oncologic care



or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy-Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. They concluded that among patients with metastatic non-small cell cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, those receiving palliative care had less aggressive care at the end of life but longer survival.

A pioneering descriptive study conducted by Beck and Falkson (2001: 82) explored the prevalence and patterns of cancer pain management in South Africa. The specific aims of this study were (1) to document the prevalence of pain among cancer patients in inpatient and outpatient settings; and (2) to describe patterns of cancer pain and patterns of cancer pain management in multiple settings in South Africa. 263 patients participated in the first phase followed by 426 patients in the second phase. In discussing the results, it was felt that the prevalence of pain in patients in active treatment centres in South Africa was consistent with previous reports of 30-40% (Beck and Falkson 2001: 82). The authors concluded that there are a significant number of cancer patients with unrelieved pain in South Africa, 30% of who were not receiving the appropriate level of analgesic. It was also felt that the research likely underestimated the problem as it excluded those individuals who do not have access to cancer care or services from non-governmental organizations. In keeping with the rationale for this research project, Beck and Falkson's research highlighted major barriers to effective cancer pain management that included key factors such as knowledge, resources, communication and the patient/provider relationship, and teamwork and professional relationships.

The current literature not only supports the early integration of palliative care for people suffering from cancer but provides evidence of significant unmet need in the area of

cancer pain in South Africa. As a way forward to improve access to palliative care to patients and families Defilippi and Cameron (2007: 556) state that HPCA's vision is to have all member hospices providing mentorship and become palliative care resource centres to government departments, the community, and faith-based organizations in health districts throughout the country.

## **2.4 THE RATIONALE FOR THE INTEGRATION OF SERVICES IN SOUTH AFRICA**

Since it came into power, the aim of the South African Government of National Unity has been to reduce disparities and inequalities in health service delivery and to increase access to improved and integrated services. These services were to be based on the PHC approach as outlined at Alma Ata 1978 and the Reconstruction and Development Programmes (RDP) (ANC 1994), in which the government created a framework for readdressing the imbalances, and rectifying the fragmented and inequitable health services in the country. This is re-iterated by the Constitution of the Republic of South Africa (1996), in the Bill of Rights Chapter 2 which pays special attention to, among others, the right to have access to healthcare services, hence a need for integration of palliative care in the caring of cancer patients in oncology clinics. According to HPCA (2011) the primary goal of hospice care is the palliation of patients' physical and mental suffering. The advantage of hospice care is that it can be delivered wherever the patient is. It may be hospital-based care. It can also be delivered in prisons, schools, the workplace, nursing homes, and in a patient's home, allowing death to take place at home or relevant institution optimizing the relief of pain and other symptoms, increasing patients' satisfaction and increasing cost effectiveness.

## **2.5 MODELS THAT INCLUDE ONCOLOGY AND PALLIATIVE CARE**

In terms of the integration of palliative care and oncology, it is important, particularly in developing countries, that palliative care programmes should offer a flexible approach, adaptable to the needs and resources of each setting. From the available literature, when comparing models of palliative care, several factors need to be taken into consideration, including the number of clients, the type of care required, the distance between clients, the availability of public transport, the availability of staff and volunteers and overall access to healthcare resources and medication.

### **2.5.1 A community-based approach**

According to Kumar and Numpeli (2005: 6-7) doctors and nurses can address medical and nursing problems but the social problems can be handled by society. Neighbourhood networks in palliative care (NNPC) in Kerala, India have established a program where volunteers from the local community are trained to identify the problems of the chronically ill patients and intervene by giving help to the patients with the support of trained professionals. The aim of the NNPC is to empower the local community to look after the dying patients in the community. This programme is endorsed by the WHO as a model of excellence. It acknowledges the reality in many resource poor settings that the availability of palliative care for patients and family is patchy and this makes it very difficult to provide total care that is physical, psychosocial and spiritual care through institutionalised care, particularly, when of the 56 million people who die annually, 44 million are from developing countries (Kumar and Numpeli, 2005: 6-7).

Fainsinger et al. (2007: 367) reported that in Edmonton, Canada, 85% of palliative care patients were dying in the acute hospitals and that a budgetary cut of 25% in health spending during the early 1990s posed a problem for these patients because of the reduction of bed availability. This resulted in the development of integrated, coordinated approach to palliative care services by different representatives from different health

organisations. This programme recognised family physicians and home care as central to the delivery of primary palliative care in the community. The authors further observed that the integration and deinstitutionalization of health care services to terminally ill cancer patients was saving costs. It demonstrates the potential for a positive outcome when governments and private health organisations work together taking the care to the patients' homes.

According to Wright and Clark (2006: 222) Hospice Uganda was established in 1993 in response to a needs assessment that found that there were about 2 million people in a population of 22 million who needed palliative care. It now serves as an effective example of the integration of palliative care services across the health sector where the National Health Plan includes palliative care for care of patients with cancer and HIV and AIDS. Wright and Clark (2006: 222) has further mentioned that Uganda has made morphine available to patients by allowing midwives to prescribe Pethidine (a morphine derivative), and allowing clinical palliative care nurses and clinical officers who are specially trained and registered to prescribe morphine. In some parts of Uganda a network of community volunteer workers, provided with bicycles and basic supplies, provide supportive care in the communities and liaise with Hospice Africa Uganda in Kampala, who provide palliative care when this becomes necessary. These community based hospice programmes have increased access to palliative care significantly by providing palliative care to people within their own homes, in a way that is designed to meet their cultural and practical needs. In the next subsection the current South African approach to palliative care is described (Wright and Clark, 2006: 222).

### **2.5.2 The integrated community-based home care (ICHC) model**

As mentioned previously, this collaborative community-based model was developed and piloted by South Coast Hospice in rural KwaZulu-Natal in 1996, in response to the increasing need for palliative care brought about by the HIV/AIDS epidemic (Defilippi and Cameron 2007: 556). This led to the strengthening of relationships and

collaboration between HPCA and relevant Government departments at local, provincial and national levels as well as between non-Governmental organizations. Subsequently, HPCA was awarded three linked tenders by the Department of Health to develop a curriculum for the training of community caregivers, pilot an integrated community based home care model and develop an audit tool to measure the quality of palliative care (Defilippi and Cameron 2007: 556). The main objectives of the ICHC model were to increase the access of HIV infected people to palliative care, develop and implement a collaborative model of care in liaison with the PHC clinics and Hospitals and other relevant stakeholders by sharing resources, providing patients and their families' access to a continuum of care link home-based care to the prevention and treatment of HIV. This model allows patients to be at home and to receive integrated care from the different community development partners. A study undertaken by Uys (2000: 102), based on the Integrated Community Home Care (ICHC) model developed at South Coast Hospice, showed that on average the annual utilization of services for each patient was 2.6 days in hospital, 2.7 hospital outpatient visits, 14 clinic visits and 60 home visits. This was a pleasing downward trend from the more expensive hospital service to the more economical home-based care services. Projections showed that even a modest increase in hospital time increases the cost dramatically. The ICHC model was found to be an economical model for delivering quality care (Uys 2000: 102). This is further supported by a study that was conducted in the USA which demonstrated that the hospital palliative care consultation team improves care for adults with chronic diseases, as well as decreasing hospital costs. Palliative care patients benefited from an adjusted net saving of \$1696 in direct costs per admission and \$279 in direct costs per day, including a significant reduction in laboratory and intensive care unit costs compared with usual care patients (Morrison et al., 2008: 1783).

### **2.5.3 A Facility-Based Approach**

Mazanec et al. (2009: 324) presented The Cancer Support Team (CST) of the Ireland Cancer Center, University Hospital of Cleveland as a new model that promotes palliative care in conjunction with and as a component of disease oriented care. According to this model, oncology patients and their families facing advance lung and gastrointestinal cancers will receive an interdisciplinary plan of care based on their goals and preferences. This model is for those patients who choose hospice as well as for those who do not, where palliative care will be available from diagnosis until bereavement. Moving away from the dichotomous model of palliative care, this kind of model gives a patient a chance to choose between receiving curative treatment and at the same time as they are receiving palliative care. Nowadays, there are a number of palliative care programmes have been established in acute settings to provide consultative services (Mazanec et al., 2009: 326). This model support the WHO definition of palliative care which states that palliative care is applicable early in the course of illness, in combination with other treatments that are intended to cure.

Defilippi and Cameron (2007: 553) state that modern palliative care which developed in the United Kingdom initially provided in-patient care principally. From that original institutional model of care, a comprehensive palliative care service has developed that includes more focus on community based care such as day care, services in care homes and patients' own homes. In South Africa, the major portion of palliative care is provided in patients' homes. The report by Insideout (2011) shows that 99% of the patients are seen at home and 1% in facilities. However, it is still important for facility-based care to be available for referral for management of severe symptoms, respite care and, for some patients, terminal care. Some hospices have partnered with their local state hospitals to make access to palliative care available to hospital inpatients. In some cases palliative care wards have been established, staffed and maintained by the hospital with the interdisciplinary hospice team providing palliative care expertise. In other instances there are hospital palliative care teams which work throughout the hospital providing palliative care input to patients in all wards when required. One faith-

based hospital has joined HPCA as a member and is working towards applying palliative principles throughout the service.

## **2.6 THE ROLE OF THE ONCOLOGY NURSE IN PALLIATIVE CARE**

The literature research produced a number of articles that highlight the issues for oncology nurses in providing palliative care, mostly again sourced in countries where the services are more fully integrated. For instance, Tishelman et al. (2002: 421) emphasized the complexity of caregiving for patients with advanced cancer care. The findings from 20 focus group discussions across three different health settings in two Swedish cities revealed the everyday tension between caregiving ideals and limits imposed by the realities of caregiving in today's health system. Participants discussed the organization of care, the different relationships between patients, family members and professionals, and theoretical and experiential knowledge as equally important aspects in dealing with all concrete situations in daily practice. The importance of reflective practice, use of self and ethical reasoning also permeated the focus group discussions.

Sapir et al. (2000: 458) state that the "role of the oncologist and the oncology nurse include diagnosis, counselling, treatment administration, direct provision of support, and coordination of auxiliary supports". The role of the oncology nurse also involves transfer of information to the patients and families. In the study, patients expressed expectations of patience, trustworthiness and reliability, tact, and understanding of their psychological and social concerns from both physicians and nurses. The study team reported that patient expectations are always high regarding knowledge about the treatment of pain and the use of chemotherapy in the treatment of cancer. Pavlish and Ceronsky (2009: 404) agreed with other authors when they identified five primary nursing roles in oncology nursing: teaching, caring, coordinating, advocating, and mobilizing. In all five roles, seven professional attributes were described: clinical expertise, honesty, family orientation, perceptive attentiveness, presence, collaboration, and deliberateness.

A shortage of nurses is a reality in many developing countries that comprises patient care. For example, South Africa has 140 registered nurses per 100000 people, while

the UK has 479 per 100000 people. In terms of oncology nurses in South Africa, in 2006 there was 1 oncology nurse for every 39,400 patients (Green cited in Maree and Wright, 2008: 46). In their survey study to determine the most common symptoms of advanced cancer patients treated in a public and private hospital in Tshwane, South Africa, the unequal distribution of nurses in the public and private health care sector was felt to be a possible explanation for the fact that patients being treated at the public hospital experienced more symptoms than patients receiving private health care (Maree and Wright, 2008: 46).

The literature review did reveal a handful of studies that provided insight into the knowledge and experiences among oncology nurses of the integration of oncology and palliative care. For instance, Miraviglia et al. (2008: 123) conducted a survey study among a random selection of Texas registered nurses about their needs for education in cancer and end of life care. The findings reported that nurses' perceptions of end-of-life needs were for physical needs, 'what to expect' concerns, and transition to palliative care. However, they have to be interpreted with caution as there was a low response rate i.e. 8.3% and the participants were an unequal representation of nurses from different practice settings. A qualitative study by Mahon and McCaulay (2010: 144) involved 12 nurses from different oncological settings and looked at their personal understanding of palliative care in their practice. The findings suggested that most of the nurses could not distinguish between hospice and palliative care, believing that only patients near the end of their life should receive it and that their role in making palliative care decisions was very limited. However, given that that half the participants were advanced practitioners, the authors expressed a concern that this would limit the transferability of the findings.

Another American survey study by Beckstrand et al. (2009: 446) approached 1000 Oncology Nursing Forum members to determine the magnitude of selected barriers and supportive behaviours to providing end of life care for oncology patients. With a reasonable return rate of 41%, participants identified dealing with angry families and families who would not accept the prognosis, as well as being called away from dying



patients to tend others as the three main perceived barriers. Supportive behaviours included allowing family members adequate time with the patient when he died, having the involvement of social work or palliative care, and having family members accept that the patient was dying. It was hoped that this findings would facilitate discussion and change among the multi-disciplinary team and ultimately improve the end of life care for oncology patients and their families.

## **2.7 REFERRAL OF CANCER PATIENTS FOR PALLIATIVE CARE FOR THE CONTINUATION OF CARE**

According to Friedman et al. (2004: 73) some of the barriers to accessing hospice care relate to physicians and other health care professionals, such as lack of education in hospice care especially end of life care and difficulty accepting death. In a death denying society, patients and families can also have misinformation about hospice care that can create barriers to access. Melvin and Oldham (2009: 292) cited in their study the importance of training doctors in palliative care saying it would address their fear of losing control of patients or a fear of failing the patient. They further mentioned the importance of public education on palliative care services.

The argument has already been well made that best practice lies in advocating for the integration of palliative care services into standard oncology practice at the time a person is diagnosed with advanced cancer and emphasizes the treatment of cancer should be offered concurrent with palliative care and standard oncologic care at *initial diagnosis* (Smith et al., 2012: 309). *There is now firm evidence that palliative care when combined with standard cancer care leads to greater access, better patient and caregiver outcomes, smoother transition to end of life care, reduced economic burden for health care services* (Almedzai et al., 2004; Temel et al., 2010; Morrison et al., 2008). Yet a study by Bruera and Hui (2010) showed that despite an increase in the provision of palliative care by oncologists, there are still a large percentage of patients who are being referred late during their last days of their lives for palliative care. One of

the key barriers to early referral is the misunderstanding that palliative care is only provided at the end of life, once patients have exhausted all cancer treatment options. The authors suggest that the use of the term supportive care instead of palliative care might be conducive to earlier referrals, given that this term is perceived as less distressing by oncologists (Bruera and Hui, 2010: 4015).

A study that was conducted by Corner et al. (2002) supports the early referral for palliative care by stating that palliative care reduces hospital admissions, diagnostic and treatment interventions but improves quality of life and patient and family well-being. Earle et al. (2008: 3861) concluded in their study that if palliative care is not available, oncologists tend to continue giving chemotherapy for longer than they otherwise would. Limited access to hospice is often based on geography and rural settings, and patient social factors which have all been documented. Barriers to palliative care not only limit access to services but some patients and families also associate it with a stigma. When interviewed on the 19 January 2012, Dr Sarah Fakroodeen, Medical Director of Highway Hospice Durban in South Africa stated that while hospices in South Africa are offering palliative care early in the course of the illness, they are still receiving late referrals of patients with some patients spending one or two days on the palliative care programme before their die.

## **2.8 CONCLUSION**

The literature review has demonstrated that the way forward to increasing peoples' access to palliative care is integration across all health care services. The concept of palliative care as an intervention that can be offered alongside potentially curative treatment, on the basis of need and not of diagnosis has yet to take firm hold. In countries with fully integrated palliative care services, mostly in the West, there is growing research evidence that the early introduction of palliative care lessens unnecessary and burdensome personal and societal costs. Yet, the literature has also

revealed that there is a gap between the ideal of integration and its practical application wherever the setting.

The epidemiological picture for cancer across Africa presents a major challenge for the development of palliative care services in the future. Although the WHO definition of palliative care is the most widely promoted, a key barrier to accessing palliative care is the misunderstanding among not only the public but also among health care professionals that palliative care means end of life care. Oncology nurses have a pivotal role in navigating patients through the different transitions in their cancer journey. Current studies, looking at the experiences and knowledge of oncology nurses highlight not only the increasing complexity of the role but also the unique position that nurses are in to shape the future of cancer and palliative care. In light of the significant number of patients with unrelieved cancer pain, a major driver for this study has been a growing concern that an oncology nurse's personal understanding, knowledge and experience of palliative care may serve to limit care for patients who would benefit from it. To date, there have been no studies in Africa that have sought to understand oncology nurses' knowledge and experience of integrating oncology and palliative care. At a time when there is a lack of a local evidence base in palliative care research to influence service delivery, other than studies on physical symptomology, this project is timely.

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

An overview of the research methodology used will be described. Data collection methods and data analysis methods will also be included for discussion in this chapter. This study was aimed at collecting data from nurses who were working in oncology clinics at the two selected sites. Initially, record review was also going to be done to triangulate data collection methods. In one of the facilities, records were kept electronically. In order to access the records, the researcher was denied access as she did not have the password. Permission was sought from the University Faculty Research Committee to change the methodology as the researcher had challenges in accessing the records at the oncology clinics. Please see evidence provided (See Appendix H).

#### **3.2 DESIGN**

A qualitative, exploratory descriptive and contextual research design was used to guide this study. According to Polit and Beck (2008: 392) qualitative research is used to gain insight into people's attitudes, behaviours, value systems, concerns, motivations, aspirations, culture or lifestyles through the collection of rich narrative materials using a flexible research design. The purpose of descriptive studies is to observe, describe and document aspects of situation as it naturally occurs.

Qualitative methods of research permitted the researcher to assess the integration of palliative care in the caring of cancer patients in the selected oncology clinics in depth. The researcher's background in palliative care increased her ability for exploring the issues on oncology care. Contextualism was acknowledged as human behaviour does

not occur in a vacuum. It is necessary to provide a comprehensive description and analysis of the environment of the participants (Polit and Beck, 2008: 274).

### **3.3 STUDY SETTING**

This study was conducted at the two public hospitals that are located within the eThekweni district which is one of the eleven districts in the province of KZN in South Africa. Hospital A is a district hospital and Hospital B is a tertiary hospital. These two hospitals were chosen because they were the only public hospitals in eThekweni district that had oncology clinics.

### **3.4 STUDY POPULATION**

The target population consisted of professional nurses who were working at the oncology clinics at the two public hospitals.

### **3.5 SAMPLE METHOD AND SIZE**

A criterion sampling of all consenting professional nurses employed in the oncology clinics of the participating hospitals took part in the study. Hospital A has a total number of 10 professional nurses and Hospital B has 12 professional nurses who are working in oncology clinics. All the professional nurses wanted to participate and adjustments were made in order to prioritise clinical care and allow as many nurses as possible to take part. This meant that eight nurses from Clinic B participated. In clinic A, it was not possible to make the same arrangements due to clinical demands, the researcher arranged to meet the participants in their off duty. Only eight nurses were able to meet at the scheduled time.

### **3.6 SELECTION CRITERIA**

#### **Inclusion criteria:**

- Professional nurses who were working at the selected sites in the public urban oncology clinics for more than three months. The time frame of three months ensured that nurses with at least some experience in the clinic could meaningfully participate.
- Professional nurses who had given informed verbal consent for participation in this research.

#### **Exclusion criteria**

- Professional nurses who had worked for less than three months at the oncology clinic. However none of sample were excluded on this criteria
- In clinic B, professional nurses who were needed to carry out essential clinic services as the focus group was held in their on duty
- In clinic A professional nurses who were unable to meet in their off duty shift due to family demands

### **3.7 PROCESS INVOLVED IN SELECTION OF ONCOLOGY AND OF FOCUS GROUP PARTICIPANTS**

The recruitment involved the three stages of preparation, contact, and follow-up. The preparation stage involved finding out which hospital had oncology clinics and identifying information sources as well as key contacts. The contact stage involved negotiation with those key contacts and potential participants, confirmation, and plans for continued involvement. It also entailed obtaining permission from the Provincial

Department of Health, Medical Directors of the hospitals and Managers in charge of oncology clinics. The written permission from the Provincial Department of Health was used as the evidence that the study could be carried out among oncology nurses at clinic A and B. The nature of the study, its importance and how it was going to be conducted was explained to the key contacts and the potential participants.

Upon approval, each manager from clinic A and clinic B was asked to discuss the contents of the letter with their teams, informing them of the purpose of this study and to offer them the opportunity to participate or not. On the day of the interview, the researcher again explained the purpose of the study to the participants before proceeding and that is voluntary in nature. They were advised that they could withdraw at any time. At this point the participants gave informed verbal consent to participate in the interviews.

### **3.8 DATA COLLECTION METHODS**

The study was participative in nature and employed a focus group method, a technique of group interview that generates data through the opinions expressed by participants. The research nurse consulted widely with key people including the HPCA, a representative group of doctors and nurse practitioners from oncology, published authors in the area of oncology and palliative care, as well as her supervisor. The experience of the oncology nurses was sought through focus group interviews at work to facilitate maximum participation. The groups were used to enable the sharing of experience and opinion between oncology nurses on their provision of care.

The researcher encouraged all the participants to talk freely about all the topics and tell their stories in their own words. In preparing for the questions the researcher organised the questions from general to specific. Open questions allowed participants the opportunity to provide richer, more in-depth answers.

The interview guide was shaped in part through the process of the literature review that helped the researcher to focus on key issues, for example the professional nurses' understanding of palliative care. The researcher drew on her own extensive experience in oncology and palliative care to put this together. The list of themes for the focus group was then finalised with the supervisor.

### **3.8.1 Focus group discussion**

According to Polit and Beck (2008: 394) focus group interviews should be undertaken with about 6-12 or more people for discussion whose opinions and experiences are solicited simultaneously. The focus group was comprised of eight participants from clinic A and clinic B. The researcher guided the discussion according to the interview guide. Participants were professional nurses who had been working in the selected sites in the public urban oncology clinics for more than three months. These nurses were directly involved in caring for the oncology patients. Without the restrictions of closed-ended questions or the interviewer's opinions, participants were interviewed using the guide. It was felt by the researcher that participants needed to have at least three months clinical experience in the management of cancer patients. The room which was allocated for interview allowed for privacy i.e. patients could not listen, it was quite and comfortable. The researcher was not in uniform. She introduced herself and the research assistant. Participants were asked to sit in a circle to facilitate the discussion. A tape recorder was positioned in the optimal position for sound quality purposes. Data collection and analysis were done simultaneously. The interviews were audio taped and then transcribed into a text by the researcher. Hand written notes and memos were also utilised to provide backup information.

The researcher ensured that the participants were relaxed and interviewed in their workplace. Participants in clinic A met in the oncology clinic, at mid-morning when they



were relaxed, having refreshments and chatting among themselves. The group was comprised of eight female nurses. The discussions were conducted in English since all the participants were proficient in English. The interviewer guided the discussion using the pre-formulated interview schedule with open-ended questions and each participant had an opportunity to air their views on the topic. Due to the shortage of staff in clinic B, it was impossible to conduct the interviews during working hours. The participants all agreed to meet at the nurses' home lounge after hours for the focus group discussion. Participants were relaxed, having refreshments and chatting among themselves. The group was comprised of one male and seven female nurses.

Polit and Beck (2008: 394) state that qualitative researchers usually do not have a specific set of questions that must be asked in a particular order and worded in a given way. Therefore, more general theme-related questions are introduced to allow the respondents to tell their stories in their own way. The questions were developed with this aim in mind. Focus group interviews began with the researcher introducing herself along with the research assistant, and recapping the project with the group, talking through the practicalities of how long the session would last; what the group would talk about; the possible risks, for example emotional upset; the benefits, for example, of being able to speak up; issues of consent and confidentiality; the tape recording; the presence of another facilitator and what would happen with the data. The initial question that was asked was: 'What is your understanding of palliative care?' This was followed by open discussion, with the facilitator only asking questions that had not yet been covered. All of these areas were addressed before the following thematic questions were introduced. The following probing questions were used to facilitate the discussion:

- How would you identify who needs palliative care?
- What are the key elements of palliative care?
- Are there any palliative care providers in this district?
- What is the referral procedure of patients?

- Is there anything you want us to discuss on palliative care?
- What is the appropriate time to introduce palliative care?
- Do you provide palliative care?
- How do you integrate palliative care into oncology practice

A research assistant who is a third level student skilled in tape recording and taking accurate, written notes was used to take notes in order to provide backup information and improve the accuracy of the findings. She was briefed in detail about her role in the focus group discussions.

### **3.9 PILOT STUDY**

According to Polit and Beck (2008: 213) a pilot study is a small measure trial run with the intention of testing the methods to be used in a large study. These authors further state that the purpose of the pilot study is to prevent unnecessary expense which can be caused by failure of the study. Since the researcher is working for a palliative care organisation, the pilot study was conducted in her work place with a group of six professional nurses. No changes were required in the interview guide after the pilot study. It also became clear that the interviews would be guided by the responses of the participants and the researcher would have to probe to obtain more information from each participant.

### **3.10 ETHICAL CONSIDERATION**

Before commencement of the study, ethical clearance was obtained for the Faculty Research Committee at the Durban University of Technology (See Appendix A). Permission was also requested (Appendices B and C) and obtained from the KZN Department of Health and two hospitals (See Appendices D, E and F). The ethical considerations of the study were observed, whereupon information was given to the participants and informed consent form was provided for the participants to sign (See Appendix G). Once the FGDs began, the researcher engaged the research assistant to assist in taking detailed notes and managing the audio tape recorder.

Any qualitative study, like all the forms of research, is subject to a Codes of Ethics and good practice for the protection of the participants (Polit and Beck 2008: 170). Ethical codes are based upon a few generally accepted moral values of respect for individual beneficence, respect for human dignity and justice (Polit and Beck 2008: 171).

#### **3.10.1 Beneficence**

Beneficence stresses that the researcher has to minimize any harm to subjects or society as a whole (Polit and Beck 2008: 170). This study was conducted in the natural setting to ensure data that was rich. Before the study was conducted it was first approved by the University Research Committee and Provincial Department of Health of KZN, as well as the hospital authorities. The nature of the study, its importance and how it was going to be conducted was explained to the key contacts and the potential participants. The information about the purpose of the study, the process of data collection and analysis and how the results will be disseminated was discussed with participants.

The discussion also included the risk involved in taking part in the study. For this study there were no physical risk involved but there was potential for emotional discomfort

associated with the nature of the topic. The researcher introduced herself to the participants and explained her objective for being with them. The participants were given opportunity to ask questions about the research procedure and the purpose before giving consent to be part of the research study. During interview the researcher ensured privacy by conducting interview in nurses' tea room far away from the patients. The participants were informed that they were free to discontinue their participation at any time during the study.

### **3.10.2 Respect for human dignity**

The principle involves the right to self-determination and the right to full disclosure (Polit and Beck 2008: 171). The rights of the participants to decide to participate in the study were respected by the researcher. To enable the participants to make informed decision to participate in the study, the researcher provided detailed explanation on the study, including but not limited to the purpose of the study, consequences of participation or refusal to participate, and possible gains or risks associated with participating in the study. Following the full disclosure of information regarding the study, participants were asked to voluntarily sign a written consent to participate in the study. The researcher witnessed the signing and countersigned as witness.

### **3.10.3 Justice**

The principle included the participants' right to fair treatment and their right to privacy (Polit and Beck 2008: 173). The privacy of participants regarding any information relevant to them and their identity were maintained. Neither the names of the hospitals or the participants were disclosed

### **3.11 DATA ANALYSIS**

Although data analysis rarely proceeds in a step-wise manner, it is helpful to use steps to provide a structure or framework for analysis (Terre Blanche, 1999: 140). According to Burns and Grove, (2007: 97) data analysis occurs in three stages, namely description, analysis and interpretation. When data was analysed, the following stages were followed:

#### **(a) Description phase**

Familiarisation with the data through immersion in transcripts formed the initial stages of data analysis. In this phase, the transcripts were read and re-read in order to become familiar with the content. The researcher became sufficiently familiar with the transcripts and data to know where in the transcripts specific data are found and once the themes had been identified, data supporting the themes or conflicting with the themes could be utilised.

#### **(b) Analysis phase**

Qualitative content analysis is the analysis of the content of the narrative data to identify prominent themes and patterns among the themes (Polit and Beck, 2008). Data was broken down into small units. The main issues emerging from the text were identified. Key phrases in the texts were highlighted using different coloured highlighters and these verbatim phrases were cut out and stuck onto cards, clustering the issues with similar content. The cards were labelled with headings directly describing the content. The phrases were coded to identify which interviews they had been taken from. Thereafter data was coded according to the content they represented and coded material was grouped based on the shared concepts. The cards were used to identify categories as groups of issues and to formulate themes in order to address each objective. Data that appeared to relate to different sub-themes were further compared and analysed to

identify the data most relevant to each theme. In this way, the researcher was able to develop themes and sub-themes.

### **(c) Interpretation**

The researcher interpreted the data according to her understanding, using themes and sub-themes identified during the analysis phase, and supported her interpretation with the use of extracts from the interviews to reduce bias.

## **3.12 TRUSTWORTHINESS**

Trustworthiness refers to the quality value of the final results and conclusion research in a qualitative research using credibility; dependability; conformability; and transferability Pilot and Beck (2008: 768). Lincoln and Guba's (1985: 300) criteria were employed in this study:

**Credibility:** Credibility means being authentic to the data. To achieve this, the researcher utilised several measures. The researcher discussed the process of data analysis with colleagues and the research supervisor. The data and categories discovered were discussed with the research supervisor at regular intervals. Following the FDGs and their transcription, the researcher shared the transcripts with the participants for review and correction of the researcher's interpretation of the meaning of the data.

**Dependability:** Dependability is concerned with the stability of the data in the study. An audit trail was developed. Records kept include an audio compact disc of interviews and FDGs, transcripts in the original language the interviews were conducted in as well as summaries of interviews. Although the researcher coded the interviews herself, the

data and analysis were checked for discrepancies through member checking with the participants after the data was analysed.

**Conformability:** According to Lincoln and Guba (1985: 320-321), conformability refers to the degree to which the researcher can demonstrate neutrality of the research interpretations. To meet the criteria for conformability, the researcher went back and forth into the data, notes and audiotape and consulted again with participants to confirm that the findings reflected their responses, not the researcher's own constructions and biases. When this was done, the findings were written in a descriptive form indicating the major themes, categories, concepts and their relationship with one another.

### **3.13 CONCLUSION**

The methodology that was appropriate for this study was in the form of a qualitative, explorative, descriptive and contextual research design. This method was found to be appropriate because of its practical applicability in helping to conduct the study. The participants were recruited from two oncology settings, i.e. two oncology clinics. Data was collected utilizing focus group interviews using a prepared study guide. A research assistant was recruited. The information was recorded using an audio tape recorder. Data analyzed occurred in three stages, namely description, analysis and interpretation. Ethical considerations were followed. The data analysis followed the three stages of description, analysis and interpretation.

## **CHAPTER 4**

### **PRESENTATION OF THE FINDINGS**

#### **4.1 INTRODUCTION**

This chapter presents the results of the two focus group discussions that were conducted with the Professional Nurses (N=16) and seeks to identify emergent themes and sub-themes from the data analysis. For the purposes of validity, the transcriptions were checked by the research assistant and a research associate before it was analysed. Commonalities and emerging themes in the participant responses were identified by the researcher as well as research associate. This was done by hand with both parties. These commonalities were grouped into sub-themes and these subthemes were then logically grouped together to form three main themes. Relevant quotations from participants were used to justify the selection of subthemes. After the data was analysed, the researcher identified three main themes which were classified as follows:

1. Meaning of palliative care
2. Integrated care approach
3. Continuity of care through referral to palliative care

#### **4.2 MEANING OF PALLIATIVE CARE**

The participants of this study defined palliative care in a number of different ways. Working definitions of palliative care were directly drawn from clinical experience. So, what palliative care was, where it was provided and who should be involved was shaped as much by these clinical experiences as by other factors, such as their work environment and other professional colleagues such as physicians. The participants were all professional nurses with only one having a palliative care certificate. All participants had more than one year experience in the oncology clinics A and B.



Based on the findings of this study, the researcher identified the following sub-themes linked to the meaning of palliative care:

- a) 'Going down' or the last stage
- b) Palliative care as treatment/management of symptoms
- c) Palliative care as holistic family-centred care

#### **4.2.1 'Going down' or last stage**

Some participants defined palliative care as care for patients in the last stages of their illness and that often it is the doctor who determines if the patient is eligible for palliative care. Normally this is seen as the stage when a patient is beyond curative treatment and not coping with their daily activities. Their views are expressed in the following excerpts:

*"Palliative care is given when patient is suffering from the terminal disease at their last stage and when they are also going down. [Respondent 1] [Oncology Clinic A]*

*"When the patient is on the last stage, when you see that they are going down because they don't need any active treatment, those are the patients who I think they need palliative care" [Respondent 1] [Oncology Clinic B]*

*"You cannot introduce palliative care for example at the stage one or two breast cancer, patients are still going to have treatment according to my knowledge. Unless as you observe them going down or the cancer has metastasized and when it is affecting the bones or when the curative treatment is no longer working.[Respondent 4] [Oncology Clinic B]*

It is interesting to note that all three participants used the words “going down” in their expressing their understanding of palliative care. Two of them also used the expression “last stages” and all considered palliative care being introduced only once the patient’s treatment was no longer working.

#### **4.2.2 Palliative care as treatment/management of symptoms**

The participants also mentioned that they could identify those who needed palliative care by looking at the patient’s file and if the patient had been presenting with the same problem for a long time.

This was expressed in the following ways:

*“By referring to the medical records of the patients to check the duration of the illness and identifying the diagnosis; this will give an indication that the patient needs palliative care to manage the patient’s problems.”* [Respondent 3]  
[Oncology Clinic B]

*“It is important to record all patient’s complaints as know when to initiate palliative care to deal with patients complains The patient may have been presenting with one problem for the long time regardless of the treatment that he/she may be receiving, this can be identified in patient’s file.”* [Respondent 5]  
[Oncology Clinic B]

All participants agreed that the patient’s records could be an indication of the need to start palliative care, because they would show the duration of the illness and the medical history, if the patient has been presenting with one problem for a long time regardless of the treatment. In this way, the medical records become a signpost for initiating palliative care.

According to the participants, when the cancer has spread beyond the curative phase, it is only then that palliative care takes over, particularly in areas such as pain management. In this regard, for the participants palliative care is closely associated with management of physical symptoms only. Their views are expressed in the following excerpts:

*“According to my understanding palliative care is the stage when patient is no longer responding to curative treatment at that stage the only thing that can help is palliative because it prevent the spread of cancer and control the pains and the symptoms.”* [Respondent 4] [Oncology Clinic B]

*“I have notice that palliative care pain medication is given when doctors have tried everything to help the cancer patients, when all have failed this where they have introduced pain medication as to control and the stopping the cancer to spread.”* [Respondent 1] [Oncology Clinic B]

*“Pain management is only given when the patient is at the palliative care stage usually this is happening at the hospices.”* [Respondent 1] [Oncology Clinic B]

There seems to be a general consensus among these participants that pain medication/management is only introduced when more active treatment has failed. Two of the participants even associated palliative care with stopping the spread of the cancer.

### 4.2.3 Palliative care as holistic family-centred care

All the participants raised the importance of holistic care. All the participants agreed that emotional support, cleanliness, feeding, support, telling the truth, dignity, monitoring the psychological state, pain control, comfort of the patient and physical health were all the key elements of holistic care. The participants viewed emotional support as making the patient comfortable by feeding and cleaning the patient, telling the truth about the condition of the patient and maintaining the dignity of the patients as the important key elements of palliative care. Regarding the physical state of the patients, the participants emphasized the importance of making the patient comfortable by making sure that the patient is pain free. This was expressed in the following ways:

*“When comes to palliative care patient should receive holistic care for example emotional support, hygiene, feeding, psychological support like telling the truth about the patient’s condition and this should also be provided by the family. Nurses and doctors need to attend to problems like pain and treatment.”*  
[Respondent 5] [Oncology Clinic A]

*“Although pain control is important, comfort of the patient is also important and should be provided by the family because they are the ones who spend more time with the patient.”* [Respondent 2] [Oncology clinic B]

*“Palliative care is rendered by the families to the patients who are chronically ill or suffering from untreatable diseases when patients are at home whereby you render holistic care according to surfacing needs of that time.”* [Respondent 2] [Oncology clinic B]

There is an emphasis by the participants on the important role the family play in the holistic care of the patient. All the participants agreed that palliative care also needs to

involve the family. Their concern was that families are not being involved early enough to understand what is going on with the patient; that they are only involved when the patient is terminally ill. This was expressed by participants in these quotes;

*“Patients’ families have no clue of what is palliative care is, families are only involved when the patient is about to go to the hospice and it’s hard for the families to accept that the patient has to go to the hospice.”* [Respondent 6] [Oncology Clinic A]

*“Palliative care also involves family because when the patient is discharge after he has been admitted to the ward for three or five day, the family is being told how to support that particular patient physically, psychologically and spiritually, it can be the child, or an adult, but at this stage you find that the patient is very sick and family find it difficult to cope because the family was involved late during the course of illness”* [Respondent 5] [Oncology Clinic A]

*“You have to assess the entire situation of the family, the psychological state, their physical health where they are at if they are able to do certain things for the patient.”* [Respondent 8] [Oncology Clinic B]

The participants also acknowledged the burden of care, including the physical, psychological, social and spiritual issues that families are facing in caring for patients.

### **4.3 CONCEPT OF INTEGRATED CARE APPROACH**

Some of the participants mentioned that it is not only hospices that are providing palliative care. Oncology clinics also provide palliative care, and they are the first people who provide palliative care because they are the ones who make the first contact with the patients before they are being transferred to the hospices. Participants raised the concern that in the hospital setting they don't only have palliative care patients, but they also have other patients who are still on the curative medication, and they are not sure how long they need to be on curative medication before they start with palliative care. The researcher identified the following sub-themes linked to the concept of the integrated approach:

- (a) Providing Palliative care in an oncology clinic
- (b) Holistic care

#### **4.3.1 Providing Palliative care in an oncology clinic**

The participants had different opposing views regarding palliative care and the way it was integrated into the oncology clinic. Some participants believed that when they were conducting health education on chemotherapy that is part of palliative care and made the link between the holistic kind of care they are providing and palliative care. Some mentioned that because of staff shortages and their own lack of knowledge of palliative care, they are not able to provide the palliative care they should be providing. They just “push” or refer patients to hospice where they start palliative care. Some participants also acknowledged that patients are not receiving enough palliative care and expressed a desire to integrate palliative care more.

The views are reflected in the following responses from some interviewees:

*“We do render palliative care to our patients, how we provide palliative care here at the Oncology clinic 1 when patients come to us we give them health education*

*concerning chemotherapy, the chemotherapy they are getting.” [Respondent 6]  
[Oncology Clinic B]*

*“I think we do palliative care every day. In all the years working at oncology that is all I know, from the time patient walks in we look at them holistically. You are always doing palliative care not only when they come for chemo today but even when the patients are at home we provide telephonic palliative care.”  
[Respondent 8] [Oncology Clinic B]*

*“...Although we are providing chemo palliative care but I am not sure if it is the same kind of palliative care provided by the hospices”. [Respondent 6] [Oncology Clinic B]*

*“...It is difficult to provide palliative care in this clinic because we always short staff, we just push the patient to the hospice where they will start with palliative care”. [Respondent 8] [Oncology Clinic B]*

*“My knowledge when comes to palliative care is very limited, I would love to spend sometimes at hospices to increase my knowledge on palliative care so that I can. [Respondent 1] [Oncology Clinic A]*

*“.....I don't think our patients are receiving enough palliative care, it will be good if we can include palliative care in the caring of our patients”. [Respondent 3]  
[Oncology Clinic A]*

### 4.3.2 Holistic care

Beyond the notion that oncology treatments could be considered palliative, and therefore form part of an integrated care approach, some participants also recognized the opportunity this provided them to provide holistic care to their patients. The following are the responses from some participants:

*“Holistic care is the part of our work we are not only attending to the physical need of the patients but we provide holistic care which forms part of palliative care”.* [Respondent 2] [Oncology Clinic B]

*“...My belief is that we are providing palliative in this clinic and this gives us an opportunity of providing holistic care”.* [Respondent 2] [Oncology Clinic B]

*“I think we do palliative care every day. When patients come for chemotherapy we give palliative care which is holistic care.* [Respondent 2] [Oncology Clinic B]

*“...All the years working at oncology that is all I know, from the time patient walks in we look at them holistically”* [Respondent 1] [Oncology clinic B]

*“You are always doing holistic palliative care not only when they come for chemo today but seven days when the patients are at home.”* [Respondent 2] [Oncology clinic B]

Generally, for these participants, it might be concluded that they are saying that when they are giving holistic care to their patients, they see this as providing palliative care.



## **4.4 CONTINUITY OF CARE THROUGH REFERRAL TO PALLIATIVE CARE**

The participants had varying degrees of awareness of the different palliative care services available to their patients. The majority of the participants reported that they had never visited a hospice and they wished they could see how the patients are being looked after at the hospice. Related sub-themes were

- (a) Unclear referral process
- (b) Palliative care in an oncology clinic
- (c) Lack of knowledge of available hospice resources
- (d) Shortage of staff

### **4.4.1 Unclear referral process**

All of the participants cited that they have a list in the doctor's consultation rooms with the names of the hospices and the contact details, but that all of the hospice services were not on the list which was last updated in 2000 by the Cancer Association. Participants raised concerns that they were not aware of all the hospices in the province; they only mentioned a few hospices to which they were referring patients and that they were using an out-dated list which was provided by the Cancer Association:

*"...We don't have the list of hospices for the country. We just know those who are around us. Sometimes we feel sorry for the patients because sometimes when we refer them out if they are in bad condition and they are not well."*  
[Respondent 1] [Oncology Clinic B]

*"...There is a list of hospice names, it is from 2000 and has never been updated since I started working here. This list was given to us by the Cancer Association."*  
[Respondent 8] [Oncology Clinic A]

Another issue raised by participants regarding the referral process was the extent of their role in referring patients to palliative care or hospice services. They saw this very much as a medical decision that they had very little input into.

*“When comes to the referral of patients to hospice I depend on the doctor because they are the ones who always refer patients to hospice”.* [Respondent 3] [Oncology Clinic B]

*“Sometimes it disturbs me to see the patient who is very sick and the doctor doesn’t refer to hospice”* [Respondent 1] [Oncology Clinic B]

In describing their relationship with hospice and palliative care services participants expressed mixed views. Some took the view that hospices weren’t actively engaging with their clinic or were sometimes a source of frustration while others saw the value of working closely with palliative care services.

*People who work for Cancer Association are very active in the department, they come and help us but I have never seen any people from hospice in the oncology department”.* [Respondent 8] [Oncology Clinic A]

*“Sometimes we get frustrated when we refer patients for admission and get told that they don’t have beds for admission. With our understanding hospices have enough beds and the patients stay in until they die.”* [Respondent 1] [Oncology Clinic B]

Some participants saw value in improving their relationships with hospice/palliative care services, not only to improve the care their patients received but also to increase their understanding of those services.

*“I think it would be if we could be given a list of hospice names and also to have someone who can visit patients at home who can communicate with us to give us the feedback about the condition of the patient after we have referred the patient to hospice.”* [Respondent 5] [Oncology Clinic A]

*“There are only two of us who have seen a hospice. Some of the nurses haven’t been to a hospice. It makes it difficult to explain to the families about hospice if yourself you don’t have enough information about hospice if the patient has to be referred to hospice.”* [Respondent 1] [Oncology Clinic A]

#### **4.4.2 Lack of knowledge of available hospice resources**

Participants spoke of their own lack of knowledge and information about hospice resources.

*“I am not sure when patient should be admitted in the Inpatient of Unit hospice ward and which hospices has in-patient of units, we need clear information on this”* [Respondent 1] [Oncology Clinic A]

*“We are not aware of all the services and resources available in hospices. I wish we can have that information at hand in case we need it.”* [Respondent 1] [Oncology Clinic A]

The participants also expressed a wish that hospices would be more actively involved in their clinics as reflected below:

*“The hospice needs to come and present to us about the palliative care and the services available and how to pay for all these services”.* [Respondent 6]  
[Oncology Clinic A]

*“Hospice needs to come more often to the department to inform us about the new developments with the availability of their resources”.* [Respondent 7]  
[Oncology Clinic A]

There was a desire among participant to improve the communication and continuity of care between the services. One of the participants wished that the patients could be followed up at their homes after they had been referred to the hospice and that they could be informed about the progress or the condition of the patient. This need is noted in the quotes below:

*“I wish the hospice nurses could do follow up on their patients at home and record their condition. The patient would then bring these records along when they come to the oncology clinic for a check-up so it will be easier for us to know how the patient was doing when they were at home”.* [Respondent 4] [Oncology Clinic B]

*“As nurses working in the oncology clinics we can appreciate it if we can get the feedback about the patients’ conditions on how they are doing at home after the referrals, unfortunately nobody gives us a feedback on how the patient is doing.”*  
[Respondent 5] [Oncology Clinic B]

#### **4.4.3 Shortage of staff**

Shortage of staff was another issue; participants raised the concern that because of the shortage of staff they don't have time to talk and listen to the patients so they are always in a rush to finish work and they end up just pushing patients to hospice.

This was expressed in the following ways by the participants:

*"There is a shortage of staff in this hospital even if you want to talk to the patient you feel as you are wasting time. I wish they can employ more nurses to come and work in this department".* [Respondent 6] [Oncology Clinic A]

*"Sometime patients want to talk but because there is no time, we do not talk to them."*  
Respondent 8] [Oncology Clinic B]

*"Due to the shortage of staff we don't have time to spend time with patients listening to them, we are always in a rush and I always feel guilty that one is sometimes is missing out something the patient might be concern with especially if you see that the patient wants to talk."* [Respondent 8] [Oncology Clinic B]

#### **4.5 CONCLUSION**

This chapter presented the results of the two focus group discussions that were conducted with Professional Nurses (N=16) working in selected oncology clinics in the eThekweni district in KZN. In the analysis of the data three main emergent themes were identified from the direct experiences and opinions of the oncology nurses. These were:

1. Meaning of palliative care
2. Concept of integrated care
3. Continuity of care through referral to palliative care

Sub-themes for each emergent main theme were also developed and are highlighted in Table 1 below:

**Table 1: Summary of themes:**

<b>Themes</b>	<b>Meaning of palliative care</b>	<b>Integrated care approach</b>	<b>Continuity of care through referral to palliative care</b>
<b>Sub-themes</b>	'Going down' or last stage	Providing palliative care in oncology clinic	Unclear referral process
	Palliative care treatment/ management of symptoms	Holistic care	Lack of knowledge of available hospice resources
	Palliative care holistic family-centred care		Staff shortage

The emphasis in this chapter was on presenting the data analysis, which will be discussed in greater length in the next chapter.

## CHAPTER 5

### ANALYSIS AND DISCUSSION OF RESULTS

#### 5.1 INTRODUCTION

The original aim of this study was to assess the integration of palliative care and oncology in a clinical setting in South Africa. The momentum for the study came directly from the researcher's own clinical experience of caring for cancer patients and observing that these patients were often referred late to hospice and palliative care services at a very advanced stage of their illness. Some died within one or two days of referral. The researcher was also aware that most of the studies in this area have been carried out in countries where palliative care is fully integrated with other health care systems. Palliative care research in Africa is in the early stages and there is a need to produce more local studies that reflect the African context. With this in mind, the researcher also wanted to undertake a study that would have some influence on the delivery of palliative care for cancer patients in South Africa, where the incidence is not only rising sharply but also the unmet need for managing essential quality of life issues such as pain management, emotional, psychological, social and spiritual aspects of living with a life threatening illness. For methodological reasons this study could not live up to its remit, for example to fully assess the integration of palliative care and oncology in a clinical setting as this would have involved a more comprehensive study which was not feasible at this time. The author has already offered an explanation of the issues in Chapter 3 but it meant that the focus of this study became more exploratory concentrating on one important aspect of integration, which is the knowledge and experience of oncology nurses.

Chapter 4 focused on the presentation of the findings. This chapter follows with a discussion of the findings in the light of the three objectives that were set out in the beginning. These were to:

- (a) Describe professional nurses' understanding of palliative care.
- (b) Describe the referral process to hospice palliative care.
- (c) Determine the role of the oncology nurse in the referral process

Three themes with associated sub-themes evolved from the analysis of the results.

## **5.2 DESCRIBE PROFESSIONAL NURSES' UNDERSTANDING OF PALLIATIVE CARE**

The results of this study revealed that participants' definitions of palliative care are consistent with palliative care principles namely holistic care, family-centred, psychosocial focus and spiritual support services. However, the participants defined palliative care in a number of different ways and working definitions of palliative care were directly drawn from clinical experience and their training. The participants' understanding of palliative care was also shaped by their level of experience and previous training in palliative care. Some viewed palliative care as a 'single story' only involving pain management or another kind of treatment, unaware of its other possible benefits in terms of emotional, psychosocial or spiritual support. Some participants used the words "going down" in expressing their understanding of palliative care. Some of them also used the expression "last stages" and all considered palliative care being introduced only once the patient's treatment was no longer working.

Most participants indicated that they applied palliative care practices only toward the end of life rather than across the continuum of oncology care. This point of view differs substantially from the WHO (2002) definition of palliative care which is broadly recommended by The Worldwide Palliative Care Alliance (Gwyther and Krakauer 2009:2) and supports the early integration of palliative care into the disease journey of someone diagnosed with a life threatening illness. At the same time, when one compares this perception to existing literature, (Pavlish and Ceronsky 2007; Pavlish and Ceronsky 2009; Mahon and McCauley 2010:147), it is clear that it provides even further evidence that different definitions and perceptions of palliative care are common in clinical oncological practice. Pavlish and Ceronsky (2009) argue that the limit of the effectiveness of palliative care programs and the gaps in care and services for patients and their families is usually caused by definitional inconsistencies which may result in



delayed referrals and role confusion. This is further supported by Mahon and McCauley (2010: 144) who state that perceptions of palliative care limit opportunities for optimal care of patients and families. Clearly, their understanding of palliative care has a large influence on how nurses care for their patients and can be a major barrier leading to poor access to palliative care or late referrals to the service. The findings in this study bear this out as well.

All participants also agreed that the patient's records could be an indication of the need to start palliative care, because they would show the duration of the illness and the medical history, if the patient has been presenting with one problem for a long time regardless of the treatment. In this way, the medical records become a signpost for initiating palliative care. In keeping with their understanding of palliative care as end-of-life care, the participants felt that only a doctor could determine whether a patient is eligible for palliative care or not, although they themselves have a sense of this from looking at the patient's file over a long period of time. It is perhaps understandable that they found it hard to know when to introduce palliative care if the patient didn't fit into 'either' life-prolonging 'or' palliative care category, as described by Byock (2000: 123) where these approaches are seen as mutually exclusive. Equally, the tendency to 'let the doctor decide' seems more appropriate if the decision is solely based on a clinical decision of withdrawal of active treatment or not. However, this hierarchical approach very much differs from the multi-disciplinary team work that is considered paramount in palliative care, where the patient and family are considered to be active partners in a team where doctors, nurses and social workers, among others, work together with the primary care provider (Wikipedia, 2012). Another study by Nilmanay et al. (2010: 393) highlighted the importance of the multi-disciplinary approach to palliative care, when their findings demonstrated that suffering is an experience of the whole person, while the focus of medicine is likely to be only on the diseased body.

According to the participants, when the cancer has spread beyond the curative phase, it is only then that palliative care takes over, particularly in areas such as pain management. In this regard, for the participants, palliative care was closely associated

with management of physical symptoms only. There seems to be a general consensus that pain medication/management is only introduced when more active treatment has failed. The participants' understanding of palliative care is the most often a reflection of their lack of formal education in palliative and end of life care. The consequences of introducing palliative care in the last stages of a patient's illness are considerable, in terms of the increased symptom burden and quality of life issues and symptoms not treated at onset become very difficult to manage in the last days of life (Sepulveda et al., 2002: 92).

There is an emphasis by the participants on the important role the family play in the holistic care of the patient. All the participants agreed that palliative care also needs to involve the family. Their concern was that families are not being involved early enough to understand what is going on with the patient; that they are only involved when the patient is terminally ill. Other participants were able to acknowledge the importance of taking a holistic approach to the care of patients and their families, acknowledging the other stories that make up the cancer journey. The responses received from the participants revealed that they understand the importance of holistic and supportive care which includes the family. Murray et al. (2004: 369) mentioned that patients who receive holistic support in the community may be less likely to require expensive admission to hospital, and often futile treatments, at the end of their lives. All the participants agreed that emotional support, cleanliness, feeding, support, telling the truth, dignity, psychological state, pain control, comfort of the patient and physical health were all key elements of holistic care. Generally, for these participants, it might be concluded that they are saying that when they are giving holistic care to their patients, they see this as providing palliative care. This is more in keeping with the first level of palliative care, as recommended by the Council of Europe (cited in Radbruch and Payne, 2010) where "all professionals working in healthcare should be confident with basic palliative care principles. However, to achieve this, palliative care has to be included in the curricula for medical, nursing and other professionals' basic education". In the South African context, the palliative care approach is not part of a nurse's basic education and the findings from the focus groups demonstrate this point well.

Some of the participants felt that their clinics were already rendering an integrated approach to palliative care for their patients. They reported that they were the first point of contact for the patients on their cancer journey and they followed them through their treatment until the point where they were transferred to hospice care. Another participant described providing palliative care in terms of helping their patients to 'talk stories', 'to talk about their personal life', as well as taking phone calls about 'what is happening at home. In this way, they might have felt that they were providing a form of integrated care. Some participants believed that when they were conducting health education on chemotherapy that is part of palliative care and made the link between the holistic kind of care they are providing and palliative care. Some participants acknowledged their own lack of knowledge of palliative care and that they were not able to provide the palliative care they should be providing. They just "push" or refer patients to hospice where they start palliative care. One participant acknowledged that patients are not receiving enough palliative care and expressed a desire to integrate palliative care more. However, it could be argued that what the participants are talking about here, in broader terms, is supportive care, more in keeping with a palliative care approach married with the basic principles, and that by glossing over areas such as pain assessment or management, or failing to tackle difficult issues such as suffering or dying, there was a real danger that key aspects of palliative care were being neglected. Most participants in the sample had a positive view of palliative care, and even an interest in how it could benefit patients and families. Continuing education supplemented by clinical experience of palliative care for oncology nurses could pave a way to overcome some of the main barriers to providing appropriate palliative care to cancer patients.

### **5.3 DESCRIBE THE REFERRAL PROCESS TO HOSPICE PALLIATIVE CARE**

The results of the study revealed that participants had varying degrees of awareness of the different palliative care services available to their patients. The majority of the participants reported that they had never been at a hospice and they wished they could see how the patients are being looked after at the hospice. The response from one of the participants shows that there is no proper communication between oncology and the palliative care team. In keeping with the definition of palliative care as end-of-life care, the participants reported they only referred patients for palliative care at hospices when the curative medication is no longer working. This ignored the widely held view that basic palliative care is the standard of palliative care which should be provided by all healthcare professionals in primary or secondary care, within their normal duties to patients with life-limiting disease (Ahmedzai et al., 2004: 2192).

The participants raised the concern that hospices are not active in the oncology clinics and they wished that hospice staff could be more available at these clinics. They believed that patients would benefit from both organizations and they would have more knowledge on palliative care. Kumar (2011: 58) in a very recent study supports the notion of the availability of palliative care in the oncology clinic, saying that it is helpful to be in the oncology clinic because patients and families members are more comfortable at the location with which they are familiar. They also appreciated having someone to talk with about issues that are not easy to discuss with their oncologist. Oncologists' perceptions of palliative care vary and often it is difficult for an oncologist to say that it might be time to stop active treatment. A palliative care presence in the clinic may help physicians, because the palliative care team can then talk directly with them to get their opinions and talk through options for the family, making sure that patient gets the same message from both teams using current accurate referral materials.

The findings from the study corroborated a widely supported view that doctors in oncology clinics have become the primary gatekeepers to information on hospice and

sources of referral to hospice. Many do not discuss hospice options until late in the disease course, when patients and their families are no longer able to benefit from hospice services. A study conducted by Morita et al. (2005: 2114) in Japan, looked at the timing of referrals to palliative care units and discovered it was late or very late from the families' perspectives. The independent determinants of family-perceived late referrals were: family misconception about palliative care, inadequate communication with physicians, and families' insufficient preparation for deterioration of patients' conditions. Participants were concerned that the patients who are benefiting from hospice care are patients who are staying around the eThekweni district, and that patients coming from other districts were not benefiting from hospice care because of the lack of information on the location of other hospices. All the participants agreed that they did not have a good relationship with the hospices in terms of a referral system.

In describing their relationship with hospice and palliative care services participants expressed mixed views. Some took the view that hospices weren't actively engaging with their clinic or were sometimes a source of frustration while others saw the value of working closely with palliative care services. Some participants saw value in improving their relationships with hospice/palliative care services, not only to improve the care their patients received but also to increase their understanding of those services. There was a desire among participant to improve the communication and continuity of care between the services. One of the participants wished that the patients could be followed up at their homes after they had been referred to the hospice and that they could be informed about the progress or the condition of the patient. Kumar (2011: 58) in a very recent study supports the notion of the availability of palliative care in the oncology clinic, saying that it is helpful to be in the oncology clinic because patients and families members are more comfortable at the location with which they are familiar. The palliative care team can discuss with the patients and families issues that are not easy to discuss with their oncologist, for example the fact that it might be time to stop active treatment when the risk is weighed against the potential benefit.

## **5.4 DETERMINE THE ROLE OF THE ONCOLOGY NURSE IN THE REFERRAL PROCESS**

An issue raised by the participants regarding the referral process was the extent of their role in referring patients to palliative care or hospice services. They saw this very much as a medical decision that they had very little input into. As mentioned previously, doctors in oncology clinics have become the primary gatekeepers to information on hospice and sources of referral to hospice. Many do not discuss hospice options until late in the disease course, when patients and their families are no longer able to benefit from hospice services. The nurses in this scenario become what McMahon (2010: 147) describes as 'requestors' or 'suggestors' to the physician decision maker. In keeping with the definition of palliative care as end-of-life care, the participants reported they only referred patients for palliative care at hospices when the curative medication is no longer working.

Oncology nurses who serve as liaisons between oncologists and patients can have a positive effect on patients' quality of life by educating them about potential side effects and the availability of supportive therapies, and by bringing patients' quality of life concerns and priorities to the attention of physicians. All the participants saw their role as building trust between them and the patients and providing supportive care to the patients when they were treatment for example chemotherapy. The supportive role they played focused on educating the patient for the treatment and side effects of treatment. In raising their own concerns, participants of the study identified shortage of staff as another key barrier to adopting a palliative care approach, saying that they did not have enough time to talk to their patients or listen to their complaints and concerns. They felt, as a consequence, that they ended up pushing patients towards hospice care. The participants felt that their palliative care role and the quality of care had been harmed as a result of this shortage of staff.

Both the Constitution of the Republic of South Africa and the National Health Act 61 of 2003 mandate the National Department of Health to ensure delivery of health services to the South African society (Republic of South Africa, 1996; Republic of South Africa, 2004 respectively). This entails ensuring the provision of adequate human resources to enable the health system to deliver on that mandate. The consequences on patient care of shortage of staff are far reaching as other studies have borne out. In a survey study carried out by the Oosthuizen and Ehlers (2007: 15) among South African nurses, their findings indicated that inadequate remuneration, poor working conditions, excessive workloads, lack of personal growth and career advancement possibilities were major factors that influenced nurses' decision to leave their current employment and emigrate. Statistics from the South African Nursing Council report a decline of 42% in the number of nurses completing their training between 1996-2005 (Makoda et al., 2011:1). In a more recent study of 108 nurses working in the province of Gauteng, 77 (73.1%) had considered leaving their current employer (Makoda et al., 2011: 4). The most important factors that would influence more than 90% of these nurses' decisions to stay with their current employers related to finances, safety and security, equipment and/or supplies, management, staff and patients.

## **5.5 LIMITATIONS**

Before trying to make some concluding remarks, it is worth discussing the limitations of the study in order to put the remarks into clearer perspective. In qualitative research, concern about assessing quality has manifested itself in the many guidelines about undertaking and judging qualitative work (Mays and Pope, 2000: 1). These authors suggest some questions that might be asked about studies of this nature and the limitations of this study are reviewed in this regard.

### **5.5.1 Worth or relevance?**

The study adds to existing knowledge about the integration of oncology and palliative care in a hospital setting in South Africa. It does this by giving voice to oncology nurses and allowing them to share their knowledge and experiences. However, given the exploratory nature of the study and the small sample involved in the focus groups, it

was not possible to reach data saturation. It may have improved the relevance to have included additional individual interviews to explore topics further. With this in mind, its purpose was not to generalize to a larger population, but to make a contribution to understanding and practice in this area.

### **5.5.2 Appropriateness of design?**

This study lent itself to conducting field research based on qualitative methodology such as a focus group interview. However, the design lacked triangulation, which is broadly seen as a way of improving validity by comparing results with two or three methods of data collection. Adding in a component of participant observation might have strengthened the overall design, but would have been difficult given the practical limitations. The policy of clinic A prevented the researcher from having access to the patients' files to corroborate review records with nursing accounts. The researcher had to change her study and only conducted the focus group interviews with the professional nurses working in the oncology clinics. In clinic A, owing to a shortage of staff, all the professional nurses were not available for the focus group interview during their working hours. The researcher had to conduct the focus group interviews after hours at the nurses' residence. The analysis does not go beyond a descriptive account, but at the same time, even primarily descriptive studies can illuminate the experiences of those 'rendering' palliative care in ways that can enlighten others, leading to improvements in practice.



### **5.5.3 Data collection?**

A clear account of the process of data collection is provided with a view to establishing an identifiable audit trail for other researchers. The data does not explicitly incorporate a wide range of views, for example, patients themselves, are not represented, or other health care professionals, so in that sense, it's clear that the experiences of the oncology nurses cannot represent the sole truth about the integration of oncology and palliative care.

In spite of the limitations of the study, it does meet the objectives set out in the beginning by exploring professional nurses' understanding of palliative care, determining their role in referring patients for hospice palliative care, and understanding the referral process at the same time. In drawing some conclusions it, might be useful to understand the current state of the development of palliative care in South Africa. According to Wright et al. (2008: 470), South Africa is considered to be in a category of countries where palliative care/hospice services are reaching a measure of integration with mainstream service providers. These countries are characterized by a critical mass of activists; multiple providers and service types; an awareness of palliative care on the part of health professionals and local communities; the availability of strong, pain-relieving drugs; an impact of palliative care upon policy; the development of recognized education centres; academic links forged with universities; and the existence of a national association.

## **5.6 CONCLUSION**

While it's clear that the development of palliative care has come a long way in South Africa, the results of this study provide a snapshot of how far it still has to go in terms of achieving full integration with mainstream service providers, in this instance, oncology clinics. In these two selected oncology clinics in the eThekwinini district of KZN, the integration of palliative care in the caring of cancer patients was not being achieved.

Three themes evolved from the results of the focus groups, namely, meaning of palliative care, integration of palliative care, and continuity of care through referral to palliative care. The overall findings in these two sites were that palliative care was defined as end-of-life care only. This definitional confusion among oncology nurses continues to be a major barrier leading to poor access and late referral to palliative care services. This finding corroborates studies from America which report that oncology nurses' personal understanding of palliative care directly impacts on patients' access to it. This perception and understanding does also seem to correlate with whether or not nurses have had access to continuing education. Along with this definition of palliative care as end of life care, the nurses saw their role in the referral process as a passive one, this was very much seen as a medical decision, not multi-disciplinary. However, the referral processes were also unclear and there was a lack of information about existing hospice resources. Communication was poor between the oncology clinics and the hospice services because of the segregation of the care. Staff shortages were also highlighted as a key obstacle to adopting a palliative care approach/role.

## **5.7 RECOMMENDATIONS**

The following recommendations were identified from the findings of this study, with special reference to policy development and implementation, institutional management and practice, nursing education and further research.

### **5.7.1 Policy development and implementation**

Palliative care needs to be integrated into the existing health system and related programmes. Policy development, education and training, provision of good quality care and drug availability are considered key components of a comprehensive palliative care programme. Adequate programme management includes balanced implementation of these components, while achieving high coverage and improved quality of life among patients and their families. Providing information to lay people and healthcare

professionals by means of in-service sessions, grand rounds and community education meetings is an important part of the palliative care mission. A common misconception is that hospices are only inpatient units where patients go to die. To fight the negative effects of this lack of information, improvements in palliative care education for all health professionals is essential.

### **5.7.2 Institutional management and practice**

There is still a lack of information when it comes to palliative care and patients are still being referred late. This might be influenced by misconceptions about palliative care or a lack of information amongst the public about the services offered by the palliative care organizations. To improve access to palliative care, palliative care organizations need to improve the awareness about the work they are doing through the media. More materials promoting palliative care need to be developed and made available in all health facilities, along with more campaigns to promote palliative care. All cancer patients should receive concurrent palliative care, even if they are receiving anti-tumour therapies. All cancer centres should have a palliative care service where medical oncologists coordinate the care of patients at all stages of disease. Oncologists and the oncology nurses should be experts in the management of the physical and psychological symptoms of advanced cancer. The oncologist and the oncology nurse are the best people to coordinate the palliative care of patients with cancer.

### **5.7.3 Nursing education**

It is important to advocate, with the educational institutions that are training health professionals, for the inclusion of palliative care in their curricula. Financial support is needed to conduct research/surveys to assess the extent of the knowledge of palliative care among health professionals. Hospices and hospitals need to have a good relationship in which there is the potential for hospices to mentor those hospitals that need to expand their practical experience on palliative care. Integrating palliative care

into routine medical settings, as well as improving education in palliative care for student nurses and other multi-disciplinary students, is critical.

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# APPENDIX A: ETHICS CLEARANCE CERTIFICATE FROM THE UNIVERSITY



**Faculty of Health Sciences**

## ETHICS CLEARANCE CERTIFICATE

Student Name	N. M. SITHOLE	Student No	208 24547
Ethics Reference Number	FHSEC 005/10	Date of FRC Approval	26 FEBRUARY 2010
Qualification	M TECH: NURSING		
Research Title:	AN ASSESSMENT OF THE INTEGRATION OF PALLIATIVE CARE IN THE CARING OF CANCER PATIENTS IN SELECTED ONCOLOGY CLINICS IN THE ETHERWANI DISTRICT IN KZN		

In terms of the ethical considerations for the conduct of research in the Faculty of Health Sciences, Durban University of Technology, this proposal meets with Institutional requirements and confirms the following ethical obligations:

1. The researcher has read and understood the research ethics policy and procedures as endorsed by the Durban University of Technology, has sufficiently answered all questions pertaining to ethics in the DUT 186 and agrees to comply with them.
2. The researcher will report any serious adverse events pertaining to the research to the Faculty of Health Sciences Research Ethics Committee.
3. The researcher will submit any major additions or changes to the research proposal after approval has been granted to the Faculty of Health Sciences Research Committee for consideration.
4. The researcher, with the supervisor and co-researchers will take full responsibility in ensuring that the protocol is adhered to.
5. **The following section must be completed if the research involves human participants:**

	YES	NO	N/A
❖ Provision has been made to obtain informed consent of the participants	✓		
❖ Potential psychological and physical risks have been considered and minimised	✓		
❖ Provision has been made to avoid undue intrusion with regard to participants and community	✓		
❖ Rights of participants will be safe-guarded in relation to:			
- Measures for the protection of anonymity and the maintenance of Confidentiality.	✓		
- Access to research information and findings.	✓		
- Termination of involvement without compromise	✓		
- Misleading promises regarding benefits of the research	✓		

\_\_\_\_\_  
SIGNATURE OF STUDENT/RESEARCHER

03.03.2010  
DATE

\_\_\_\_\_  
SIGNATURE OF SUPERVISOR/S

03/03/10  
DATE

\_\_\_\_\_  
SIGNATURE OF HEAD OF DEPARTMENT

03/03/2010  
DATE

\_\_\_\_\_  
SIGNATURE: CHAIRPERSON OF RESEARCH ETHICS COMMITTEE

4/3/2010  
D

## **APPENDIX B: PERMISSION LETTER TO THE PROVINCIAL DEPARTMENT OF HEALTH**

The Research Unit

KwaZulu-Natal Provincial Department of Health

Pietermaritzburg

3200

Dear Sir/ Madam

### **RE: REQUEST FOR PERMISSION TO CONDUCT STUDY**

I am presently registered as a Masters student at the Durban University of Technology in the Department of Nursing. The proposed title of my research project is: *'An assessment of the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni District in KwaZulu-Natal'.*

Many health care professionals and people who could benefit from palliative care view palliative care as only care of the dying. This restricts referral and access to palliative care for many people who could receive significant benefit from this care earlier in the course of their illness. The study will inform the policy makers who may then rectify the gaps in the health profession. This study results can be used to assist the KZN Department of Health to improve the cancer control programme and to the develop model to integrate palliative care in the caring for cancer patients. The study will demonstrate the effectiveness of the programme to the public, to others who want to conduct similar programmes and to those who fund the programme.

I hereby request your permission to conduct a research project at your institute which include the oncology clinic and patients' files. My research proposal has been attached

for your perusal. Your support and permission to conduct the study at the Oncology Clinic will be appreciated.

Yours sincerely

.....

**Ntombizodwa Margaret Sithole**

Student Number: 20824547

.....

**Dr MN Sibiya**

(Supervisor)

.....

**Dr L Gwyther**

(Co-supervisor)

**APPENDIX C: PERMISSION LETTER TO THE HOSPITAL MANAGER: HOSPITAL A**



XXXXXX Hospital A

XXXXXXXXXXXX

XXXXXX

Durban

4000

Dear Sir/ Madam

**RE: REQUEST FOR PERMISSION TO CONDUCT STUDY**

I am presently registered as a Masters student at the Durban University of Technology in the Department of Community Health Studies. The proposed title of my research project is: *'An assessment of the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni District in KwaZulu-Natal'.*

Many health care professionals and people who could benefit from palliative care view palliative care as only care of the dying. This restricts referral and access to palliative care for many people who could receive significant benefit from this care earlier in the course of their illness. The study will inform the policy makers who may then rectify the gaps in the health profession. This study results can be used to assist the KZN Department of Health to improve the cancer control programme and to the develop model to integrate palliative care in the caring for cancer patients. The study will demonstrate the effectiveness of the programme to the public, to others who want to conduct similar programmes and to those who fund the programme.

I hereby request your permission to conduct a research project at your institute at the oncology clinic. My research proposal has been attached for your perusal. Your support and permission to conduct the study at the Oncology Clinic will be appreciated.

Yours sincerely

.....

**Ntombizodwa Margaret Sithole**

Student Number: 20824547

.....

**Dr MN Sibiya**

(Supervisor)

.....

**Dr L Gwyther**

(Co-supervisor)

## **APPENDIX D: PERMISSION LETTER TO THE HOSPITAL MANAGER: HOSPITAL B**

XXXXXX Hospital B

XXXXXXXXXXXX

XXXXXX

Durban

4000

Dear Sir/ Madam

### **RE: REQUEST FOR PERMISSION TO CONDUCT STUDY**

I am presently registered as a Masters student at the Durban University of Technology in the Department of Community Health Studies. The proposed title of my research project is: *'An assessment of the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni District in KwaZulu-Natal'.*

Many health care professionals and people who could benefit from palliative care view palliative care as only care of the dying. This restricts referral and access to palliative care for many people who could receive significant benefit from this care earlier in the course of their illness. The study will inform the policy makers who may then rectify the gaps in the health profession. This study can be used to assist the KZN Department of Health to improve the cancer control programme and to the develop model to integrate palliative care in the caring for cancer patients. The study will demonstrate the effectiveness of the programme to the public, to others who want to conduct similar programmes and to those who fund the programme.

I hereby request your permission to conduct a research project at your institute at the oncology clinic. My research proposal has been attached for your perusal. Your support and permission to conduct the study at the Oncology Clinic will be appreciated.

Yours sincerely

.....

**Ntombizodwa Margaret Sithole**

Student Number: 20824547

.....

**Dr MN Sibiyi**

(Supervisor)

.....

**Dr L Gwyther**

(Co-supervisor)

**APPENDIX E: APPROVAL LETTER FROM PROVINCIAL DEPARTMENT OF HEALTH**



**HEALTH**  
KwaZulu-Natal

**DISTRICT/FACILITY NAME**

Postal Address

Tel.: , Fax.:

Email:

[www.kznhealth.gov.za](http://www.kznhealth.gov.za)

---

Date:

Enquiries:

Ref:

Principal Investigator

Address 1

Address 2

Address 3

**RE: PERMISSION TO CONDUCT RESEARCH AT DISTRICT/FACILITY**

I have pleasure in informing you that permission has been granted to you by the District Office/Facility to conduct research on "Title of the research study".

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. The District Office/Facility will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the District Office/Facility.

Thanking you.

Sincerely

---

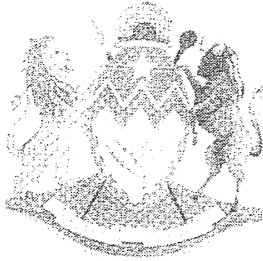
District/Facility Managers Name

District/Facility Name

---

• KINDLY RETURN ALL DOCUMENTATION WHEN REPLYING

**APPENDIX F: APPROVAL LETTER FROM HOSPITAL A**



**DEPARTMENT OF HEALTH**

**PROVINCE OF KWAZULU-NATAL**

**OFFICE OF THE MEDICAL MANAGER**  
800 Bellair Road, Mayville, 4058  
Private Bag X03, Mayville, 4058  
Tel.: 031 240 1042 Fax. 031 240 1050  
Email. Philisivemaz@ialch.co.za

04/05/2010

Reference: FHSEC 005/10  
Enquiries: Dr M E L Joshua

Ms N M Sithole  
Department of Nursing and Quality

Dear Ms N M Sithole

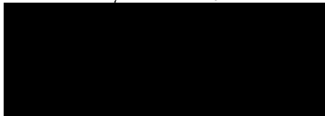
**RE: PERMISSION TO CONDUCT RESEARCH**

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on an assessment of the integration of palliative care in the caring of cancer patients in selected oncology clinics in the Ethekwini District in KZN

Kindly take note of the following information before you continue:

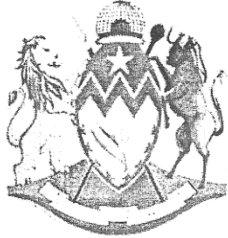
1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully



Dr M E L Joshua  
Medical Manager

## APPENDIX G: APPROVAL LETTER FROM HOSPITAL B



### **DEPARTMENT OF HEALTH**

PROVINCE OF KWAZULU-NATAL

#### OFFICE OF THE MEDICAL MANAGER

Erskine Terrace, South Beach  
P. O. Box 977, Durban, 4000  
Tel.: 031 327568, Fax: 031 3272387  
Email.:clive.rangiah@kznhealth.gov.za

24 June 2010

Dear Ms Sithole

#### **RE: PERMISSION TO CONDUCT RESEARCH**

I have pleasure in informing you that permission has been granted to you by Addington Hospital to conduct research on : **An assessment of the integration of palliative care in the caring of cancer patients in the selected oncology clinics in the eThekweni district in KwaZulu-Natal.**

Please note the following:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Please ensure this office is informed before you commence your research.
4. Addington Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to Addington Hospital.

Thank you,

Sincerely

Dr S Rangiah  
BSc, BMedSc, MMedSc, MBChB, MFamMed.  
ACLS, ACLS-EP, AMLS, PALS, ATLS, ITLS  
Acting Medical Manager



## **APPENDIX H: LETTER OF INFORMATION AND CONSENT**

**Title of the Research Study:** *'An assessment of the integration of palliative care in the caring of cancer patients in selected oncology clinics in the eThekweni District in KwaZulu-Natal'*

**Principle Investigator/s:** Ntombizodwa Margaret Sithole

**Co-Investigator/s:** Supervisor : Dr MN Sibiyi

: Co-supervisor : Dr L Gwyther

### **Brief Introduction and Purpose of the Study:**

Many health care professionals and people who could benefit from palliative care view palliative care as only care of the dying. This restricts referral and access to palliative care for many people who could receive significant benefit from this care earlier in the course of their illness. Hospice Palliative Care Association (HPCA) is only reaching 17% of patients who need palliative care. Looking at these figures only a small percentage of patients are receiving palliative care. The aim of the study is to assess how well palliative care is integrated into the caring of cancer patients in oncology clinics in the eThekweni district in KwaZulu-Natal (KZN).

**Risks or Discomforts to the Subject:** None

**Benefits:** None

This study can be used to assist the KZN Department of Health to improve the cancer control programme and to develop a model to integrate palliative care in the caring for cancer patients. The study will demonstrate the effectiveness of the programme to the public, to others who want to conduct similar programmes and to those who fund the program. The study can be replicated in other provinces and the results can be used by the National Department of Health to improve the care of cancer patients



**Reason/s why the Subject May Be Withdrawn from the Study:** None

**Participation:** Your participation is voluntary and you may withdraw from the study at any stage. You will not be forced or pressured to take part in this study for any reason. Any questions that you may have at any stage of the study will be answered by the researcher.

**Remuneration:** None

**Costs of the Study:** None

**Confidentiality:** All information concerning you will be kept private and confidential. Your identity will not be divulged even in the case of this study being published. However, some research records will be made available if it legally required.

**Research-related Injury:** None

**Persons to Contact in the Event of Any Problems or Queries:** Dr MN Sibiyá

**Statement of Agreement to Participate in the Research Study:** (I, .....subject's full name, ID number....., have read this document in its entirety and understand its contents. Where I have had any questions or queries, these have been explained to me by .....to my satisfaction. Furthermore, I fully understand that I may withdraw from this study at any stage without any adverse consequences and my future health care will not be compromised. I, therefore, voluntarily agree to participate in this study.

Subject's name (print) .....Subject's signature:.....Date:.....

Researcher's name (print): ..... Researcher's signature:.....Date:.....

Witness name (print) signature: .....Witness signature: .....Date:.....

Supervisor's name (print):.....Supervisor's signature: .....Date:.....

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## APPENDIX I: CHANGE OF METHODOLOGY

### Request to change research methodology

19 October 2010

To the Departmental Research Committee

Re: Request to change research methodology

Research title: **An assessment of the integration of palliative care in the caring of cancer patients in selected oncology clinics in the eThekweni district in KwaZulu- Natal**

My research was approved by FRC during the month of June 2010. To date I have managed to receive the permission from the Provincial KZN DOH and from both sites to conduct the interviews.

I have the following difficulties:

- Inaccessible patients' files because the policy of the hospital states that no person is allowed to get an access to the files unless you are working direct with the patient. So, I will need to have a password to access the patients' files from the computer.
- Dr Govender the oncologist who is the second in charge of both oncology clinics (Addington and Nkosi Albert Hospitals) attested that I will not be able to get any information from the patients' files because the oncologists are not recording accurate palliative care information; so my research findings will be skewed.

I therefore request the permission from the FRC to change my research methodology from using the patients' files to interviewing nurses only. I believe conducting interviews will greatly enrich information rather than using files.

Mrs NM Sithole

M Tech Student  
[Redacted Signature]

Date.....

19/10/2010

Dr MN Sibiyi

Supervisor  
[Redacted Signature]

Date.....

19/10/2010