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THE NEED FOR PALLIATIVE CHEMOTHERAPY. A PATIENT, FAMILY AND NURSE PERSPECTIVE

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A research report submitted in fulfilment of the requirements for the degree Master of Science: Nursing in the Faculty of Health Science, University of the Witwatersrand

Supervisor: Prof JE Maree

August 2015

DECLARATION

I declare that the study on **THE NEED FOR PALLIATIVE CHEMOTHERAPY. A PATIENT, FAMILY AND NURSE PERSPECTIVE** is my own work and all the sources consulted, used or quoted are reliable and that this work has not been submitted previously in any institution.

SIGNATURE _____

DATE _____

DEDICATION

With love to my beautiful daughter Erin. May you reach great heights in your chosen career and be an inspiration to all that you meet along the way.

“For I know the plans I have for you,” declares the Lord, “plans to prosper you and not to harm you, plans to give you hope and a future”

Jeremiah 29:11

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- All the participants who shared their experiences with me. It was an honour to share with you.
- GVI Oncology for giving me this wonderful opportunity to further my studies and broaden my horizons.

ABSTRACT

The objectives of the study were to gain insight into what motivates cancer patients to undergo palliative chemotherapy and how they experience the treatment. An exploratory qualitative design was used. The research setting was a private ambulatory cancer care centre in Port Elizabeth. Purposive sampling was used and data saturation determined the sample size. Data were gathered by means of qualitative interviews guided by an interview schedule and analysed. Eleven patients participated in the study; diagnosed with various cancers. Three themes arose from the data: the hope and decision: *"I want to live longer";* the good and the bad: *"fatigue is the biggest stumbling block"*; the sources of support, God, the family and others: *"it makes me feel normal".* Participants agreed that palliative chemotherapy gave them hope; some still hoped to be cured, some hoped to have time to do what remains to be done whilst others wished for additional time with their families. Eleven family members participated in the study. Three themes arose from the data: chemotherapy gives hope: *"It is not over yet";* sources of support: *"I try to do things for him…"*; quality of life: *"making the most of the time we've got".* For the family palliative chemotherapy brought hope – hope for comfort and cure. It was a positive experience for the family members as they witnessed an improvement in quality of life. Eleven nurses participated in the study; all females with oncology experience. Two themes arose from the data: clinging to hope: *"They still think there's hope"*; the positive influence of palliative chemotherapy: *"Palliative chemotherapy is a positive experience for me"*. The nurses believed that patients consenting to palliative chemotherapy had false hope and that they were pressurized by family members to undergo chemotherapy. In general nurses experienced palliative chemotherapy as positive when patients' quality of life improved and symptoms were relieved. Improved quality of life was important to all groups that participated in the study. The study provided evidence that palliative chemotherapy gave patients and their families hope, hope to live longer and have a better quality of life. Despite experiencing many side effects, of which fatigue was the worst, patients and their families persevered in order to have more time together. Although nurses were of the opinion that patients often had false hope, they still found that caring for patients receiving palliative chemotherapy was a positive experience, especially when they saw an improvement in the patients' quality of life.

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Cancer is a highly complex disease which knows no borders, is devastating and adds an immense burden on patients and their families (World Health Organization and International Union Against Cancer, 2005). As a progressive disease, more than 50 percent of cancer patients will enter the palliative stage, where the focus is on relieving suffering, psychosocial support and attaining closure near the end of life (Lo, Quill & Tulsky, 1999). However, various treatment options are available to the patient when cure is no longer possible including supportive care (also referred to as watchful waiting), palliative chemotherapy, (Koedoot et al*.*, 2004) palliative radiotherapy, a combination of radiotherapy and chemotherapy and even investigational therapy (Meyers et al*.,* 2004). According to Koedoot et al. (2004), palliative chemotherapy is tumour focused and aims at enhancing or maintaining the quality of life of the patient by decreasing the size of the tumour. Unfortunately palliative chemotherapy is associated with side effects and when compared to watchful waiting, seems to differ only slightly in terms of survival time. In 1997, Gregory *et al.* (1997) found that chemotherapy has failed to prolong the life of women with metastatic breast cancer.

Medical ethicists, medical practitioners, as well as the general public recognise the right of the patient with cancer to be fully informed about his/her diagnosis and to participate in treatment decisions. Patients would expect to be informed about their illness, the available treatment, the risks and benefits of the treatment and their prognosis (Koedoot et al*.,* 2004). Brundage et al. (2001) found a substantial percentage of patients want to be part of decisions regarding the treatment which would be best for them. Yet, despite self-determination not being disputed in the Western culture, when a terminal disease becomes a reality, patients are not always able or desire to be part of the decision making process. It was found that patients who were offered palliative chemotherapy felt they had no choice and considered chemotherapy to be the only option available to them (Koedoot et al*.,* 2001). Another study by Koedoot et al., (2003) found patients had a treatment preference before meeting with their oncologist and usually stuck to their choice after being informed of

treatment options. Sweeny et al. (2007) state that cancer patients are willing to accept interventions with modest gain and ascribe the enthusiasm for therapies with low benefit to the way the data is presented in medical literature. It was also found that patients have expectations of treatment which surpasses those of their attending physician. Penson et al. (2004) agree with this statement as they found in their study, regarding the use of chemotherapy in patients with recurrent ovarian cancer, that both patients and staff were of the opinion that patients positively reinterpreted what they were told.

Studies done by Brundage et al. (2001) and Penson et al. (2004) indicate that the desire for active treatment, therefore more chemotherapy, does not come from the staff but from the patient. Bruera (2006) states the oncologist has the most influence when it comes to the patient deciding on treatment, whereas the family, partner and nurse have a more limited role. Bruera's opinion is confirmed by Grunfield et al. (2006), who state the person who most influenced the patient's decision was the oncologist, with the family only having about 39% influence. According to Doyle et al. (2001), patients expected chemotherapy to make them feel better, to delay further complications and to make them live longer. It does not seem that perceived benefits play a role in the wish for active treatment, but unrealistic expectations. Penson et al. (2004) also found patients are more tolerant to chemotherapy induced toxicity than staff. Patients also regard the prolonging of life by three months to one year more acceptable than staff.

Little is found in literature about the family's perspective and expectations of palliative chemotherapy. Vachon, Kristjanson & Higginson (1995) found families experience different stresses and have different needs at the various stages of the patient's illness. The family's concerns are for the patient's comfort, the need for information and the emotional intensity of losing the patient.

Caring for a patient with incurable cancer who struggles through multiple courses of palliative chemotherapy is not easy. When reflecting on a staff dialogue on aggressive treatment demanded by a terminally ill patient, Lintz et al. (1999) reported that the staff were uncomfortable with the patient's insistence to be treated aggressively till the end of his life. The patient not wanting to admit defeat also made saying goodbye, a need of the staff, difficult. It is indeed difficult not to give chemotherapy to a patient who wishes to be treated and even more difficult to stop treatment when a patient insists on receiving aggressive treatment. The medical oncologists Lintz, Penson, Cassem, Harmon, Chabner and Lynch (Lintz et al., 1999) agree with this statement by saying: "What do we offer him? Even though the prospect is bleak, we have to offer him something. It is hard not to."

Oncologists often decide to continue with chemotherapy because of their concern about the patient's quality of life deteriorating further if active treatment was stopped (Detmar et al., 2002).To treat or not to treat and the question when is enough enough, are two of the ethical dilemmas in caring for the patient with cancer. Despite the many questions regarding how the palliative patient should be medically managed, it is the patient-centred nurse who administers the chemotherapy and has to support the patient who is deteriorating despite receiving chemotherapy – something that is offered regardless of the bleak prospect. Braga et al. (2007) found a large proportion of patients receive chemotherapy during the last three months of their lives, including the initiation of a new regimen in the last month of their lives. It is difficult for a nurse to administer chemotherapy to a patient when she sees "failure after failure, again and again" (Jeremic & Koning, 2008:e1).

1.2 RESEARCH PROBLEM AND PURPOSE OF THE STUDY

Nurses struggle with the question of whether or not palliative patients are over treated with chemotherapy, especially when an important question "Does palliative chemotherapy palliate?" (Doyle et al., 2001:1266) is answered with the greatest improvement being in emotional functioning and not the reduction of physical symptoms. There seems to be disaccord between patients and nurses concerning palliative chemotherapy, with the significant other the unknown factor. This research problem would therefore be addressed by the following research questions: What motivates cancer patients, treated at a private cancer care centre in Port Elizabeth, to undergo palliative chemotherapy and what are their experiences with regard to the treatment. How do the family and nurses experience palliative chemotherapy?

The purpose of the study was to provide a descriptive summary of what motivates cancer patients, treated at the private cancer care centre in Port Elizabeth, to undergo palliative chemotherapy and how the patient, family and nurses experience palliative chemotherapy.

The objectives of the study were to describe:

- What motivates cancer patients treated, at a private cancer care centre in Port Elizabeth, to undergo palliative chemotherapy?
- What are these patients' experiences with regard to the treatment?
- How do the family of the patient and the nurses caring for these patients experience palliative chemotherapy?

1.3 THEORETICAL FOUNDATION OF THE STUDY

The study is underpinned by Parse's Theory of Human Becoming (Parse, 1990), which postulates that individuals are open and free to choose, are accountable for the choices they made and are able to give meaning to situations. Kozier et al. (2000) states meaning arises from a person's interrelationship with the world and that the person attaches varying degrees of significance to happenings. Health is considered to be a personal commitment (Parse, 1990), a lived experience, synthesis of values, a way of living and a rhythmic process of being and becoming (Kozier et al. 2000). Nurses do not have control over individuals or their health choices (Alligood, 2014). The ultimate goal of nursing practice is quality of life from the perspective of the person or family who are living the life (Hutchings, 2002). The nurse enters the world of the sick and the family as a 'nurturing gardener, rather than a 'fix-it' mechanic' (Parse, 1990). Being truly present, the nurse encourages the patient to talk about the meaning of his/her situation. During this discussion, the patient has the opportunity to clarify insights, make discoveries and propose changes as the individuals see themselves in a new light and can give new meanings to their situations (Alligood, 2014; Parse, 1990).

It can thus be seen that knowledge development, which is guided by the Theory of Human Becoming, focuses on the lived experience of the person. The Parse nurse bears witness to the experience and changing health patterns of the person (Hutchings, 2002).

The Theory of Human Becoming is applicable to the study as the researcher, a nurse, does not have control over the patient's decision to undergo palliative chemotherapy. The researcher furthermore wishes to learn and construct the meaning of the human experience regarding palliative chemotherapy through intense dialogue with the persons living the experience, namely the patient, family and nurse.

1.4 RESEARCH METHODS

A qualitative descriptive design was selected for the study. Qualitative descriptive studies allow researchers to present a comprehensive summary of an event in the manner it occurs every day (Sandelowski, 2000). The research setting was a private ambulatory cancer care centre in Port Elizabeth. Three populations applied to the study: patients receiving palliative chemotherapy, their families and nurses caring for them. Purposive sampling (Brink, 2006) was used to select the samples. Purposive sampling, a method allowing the researcher to

consciously select certain participants, is commonly used in qualitative research as it is a recognised measure to improve the transferability of the findings. The sample sizes for each of the groups were determined by data saturation.

Qualitative interviews, guided by interview schedules (Addendum A, B and C), gathered the data. Using qualitative interviews allowed the researcher to ask an opening question followed by prompting questions and probes (Burns & Grove, 2005). The interview schedules were pretested using the first interviews. Data analysis was done concurrently with data gathering to be able to determine when the data is saturated. The interviews were transcribed verbatim and thematic analyses analysed the data. An Excel spreadsheet was used to summarise the general information of the participants.

1.5 CLARIFICATION OF CONCEPTS

1.5.1 *Cancer:* Cancer is the term used for a group of diseases in which abnormal cells multiply uncontrollably and invade tissues. Cancerous cells can spread to other areas/parts of the body through the lymphatic system and blood (National Cancer Institute, 2013).

1.5.2 *Palliative care:* Palliative care is an approach aimed at improving the quality of the life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (World Health Organization, 2012).

1.5.3 *Supportive care:* The alternative option to palliative chemotherapy which aims at Enhancing quality of life by the relief of symptoms once they occur (Koedoot et al., 2003). Supportive care is also defined as care which aims to optimise the comfort, Function and social support of the patient and their families at all stages of the illness. This includes patients with a curative illness (Cherny et al., 2003)

1.5.4 *Chemotherapy:* The use of chemical agents which are toxic to cells (cytotoxic), aimed at eradicating or reducing the overall population of cancer cells (Kinghorn & Gaines, 2007).

1.5.5 *Palliative chemotherapy:* Palliative chemotherapy refers to chemotherapy that is administered in circumstances where the influence of the treatment is insufficient to result in a significant survival advantage. However, the goal is to improve tumour-

related symptoms where the palliation/toxicity trade-off from the treatment clearly leans toward symptom relief (Archer, Billingham & Cullen, 1999).

1.5.6 *Radiotherapy:* The use of ionising radiation to interfere with the replication of cancer cells within the body (Kinghorn & Gaines, 2007).

1.5.7 *Palliative radiotherapy:* An overall lower dose of radiotherapy given to maintain or enhance quality of life (Kinghorn & Gaines, 2007).

1.5.8 *Quality of life:* Quality of life refers to the well-being of humans directed by social determinants rather than by numerical indicators such as income and production. In addition, quality of life refers to the ability to enjoy normal activities of daily living (UNdata, S.a.).

1.5.9 *Ambulatory Care Setting:* Any facility or setting which provides diagnostic, therapeutic and health maintenance services for persons not requiring stays exceeding 24 hours. The care provided is typically episodic and appointment based and can occur in a single visit or across many visits related to an acute or chronic illness or for routine periodic health maintenance (EHR Functional Outline and Standard Care Category and Select Care Setting Definitions, 2004).

1.5.10 *Medical Aid/Insurance:* Medical insurance which covers the cost of medical treatment and investigations, including cancer treatment such as chemotherapy and radiotherapy.

1.6 OUTLINE OF STUDY

The study will be presented in the following format:

Chapter 1: Orientation to the study

Chapter 2: Literature review

Chapter 3: Research methods

Chapter 4: Findings and discussion

Chapter 5: Justification, limitations and recommendations

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In Chapter 1, an orientation to the study was provided. Chapter 2 will focus on the literature pertaining to cancer and its treatment and cancer as a worldwide health problem, management of the cancer patient and caring approaches related to cancer care will be discussed.

2.2 CANCER AS WORLDWIDE HEALTH PROBLEM

As already mentioned, cancer is the term used for a group of diseases in which abnormal cells divide uncontrollably, invade tissues and can spread to other areas/parts of the body through the lymphatic system and blood (National Cancer Institute, 2013). According to Welch and Black (2010), the word “cancer” includes cellular abnormalities with widely variable natural courses leading to rapid growth, slow growth, complete cessation of growth and regression. Metastatic or advanced cancer is cancer that has spread from the site of origin to another place or organ in the body. Metastatic cancer has the same names and types of cancer cells as the primary tumour. Once a cancer has metastasised, it is no longer curable, but may still be treatable (National Cancer Institute, 2013).

Cancer is not a rare disease. According to the 2012 Globocan statistics (International Agency for Research on Cancer and World Health Organization, 2014), there were 14.1 million new people diagnosed with cancer, 8.2 million died of cancer and 32.6 million people were living with cancer (within 5 years of diagnosis) in 2012 worldwide. Of these, 645 000 were people from Africa, of which 456 000 died of cancer and 1.3 million were people living with cancer. According to the World Health Organization (2015), more than 60% of newly diagnosed cancer patients come from Africa, Asia and Central and South America. These regions account for 70% of the world’s cancer deaths.

It was interesting to note that the general age of cancer incidence is almost 25% higher in men than in women. The five most frequent cancers worldwide, ranked according to the total number of people diagnosed, were found to be breast cancer, colorectal cancer, lung

cancer, stomach cancer and prostate cancer. The five most frequent cancers in Southern Africa were found to be (ranking defined by total incidence number of cases) breast cancer, prostate cancer, cervical cancer, lung cancer and colorectal cancer (International Agency for Research on Cancer and World Health Organization, 2014).

According to the World Health Organization (2015), behavioural and dietary risks are the responsible for approximately on third of cancer deaths. These risks are high body mass index, lack of physical activity, low fruit and vegetable intake, alcohol use and tobacco use. In addition, the interaction between a person's genetic features and three categories of external agents, namely chemical carcinogens (asbestos, components of tobacco smoke and aflatoxin), physical carcinogens (ultraviolet and ionising radiation), and arsenic (a drinking water contaminant) and biological carcinogens (infections from certain viruses, bacteria or parasites) are also listed as causes of cancer. Smoking (tobacco use) is the most important risk factor for cancer as it is responsible for approximately 20% of worldwide cancer deaths and approximately 70% of worldwide lung cancer deaths. In many resource poor countries, HBV- and HPV-infection are responsible for up to 20% of cancer deaths.

Chronic infections such as Hepatitis C virus (HCV), Hepatitis B (HBV) and some types of Human Papilloma Virus (HPV) increase the risk for cervical and liver cancer respectively and have major relevance in low- and middle-income countries. Infection with HIV greatly increases the risk of cancers, such as cervical cancer and lymphomas. Lastly, ageing plays a big role in the development of cancer. Due to a build-up of risks which increase with age, the incidence of cancer rises dramatically with age. Cellular repair mechanisms tend to be less effective as a person grows older, which together with risk accumulation increased the incidence of cancer.

According to the World Health Organization (2015), cancer can be reduced and controlled by implementing strategies or methods for cancer prevention, early detection programs and management of patients with cancer. Many cancers have a high cure rate if detected early and treated adequately. More than 30% of cancer deaths could be prevented by modifying or avoiding risk factors, including: high body mass index, lack of physical activity, low fruit and vegetable intake, alcohol use, tobacco use and sexually transmitted HPV-infection. The World Health Organization (2015) advocates for various prevention strategies including vaccination against the human papilloma virus (HPV) and hepatitis B virus (HBV), the control of occupational hazards, the reduction to exposure to

non-ionising radiation by sunlight (UV) and the reduction of exposure to ionising radiation related to occupational or medical diagnostic imaging.

Primary prevention is aimed at measures to ensure the cancer never develops, while secondary prevention is aimed at detecting and treating the cancer early while in its most curable stage. Primary prevention involves reducing the risk of cancer by eliminating or limiting exposure to agents which cause cancer, for example chemicals, radiation exposure or viruses. Healthy diet, exercise and avoiding tobacco products decrease an individual's cancer risk. Secondary prevention involves the screening of individuals who are at increased risk for a particular malignancy in order to increase their chances of survival with early detection and treatment, for example monthly breast self-examination, gynaecological examination, prostate examination, mammogram and colonoscopy (Langhorne, Fulton & Otto, 2007).

Cancer deaths can be reduced if cancer is detected and treated early. The two components of early detection are early diagnosis and screening. Early diagnosis refers to awareness of early signs and symptoms in order to diagnose and treat cancers at an early stage, for example skin, cervical, breast and colorectal cancer. Early diagnosis is especially relevant when there are no effective screening methods. Screening aims to identify individuals with abnormalities suggestive of a specific cancer or pre-cancer and refer them promptly for treatment or, when possible, for diagnosis and treatment. Examples of screening methods are: HPV testing for cervical cancer; visual inspection with acetic acid (VIA) for cervical cancer in low-resource settings; PAP cytology tests for cervical cancer; mammography screening for breast cancer in high-income settings and colonoscopy for colorectal cancer in middle- and high-income settings.

Cancer is one of the most feared diseases in society today. Cancer has a strong influence on the quality of life of people (Pinto et al., 2013). Skilbeck and Payne (2003) add that the cancer experience results in unique stresses for families and patients alike, of which emotional distress is a feature along this cancer journey.

2.3 MANAGEMENT OF THE CANCER PATIENT

The main goals of a cancer diagnosis and treatment are to cure or prolong the life of patients and to ensure the best possible quality of life. This requires a careful choice of one or more of the major treatment modalities – chemotherapy, radiotherapy, surgery, or a combination

of all. Surgery or radiotherapy alone is highly successful with localised tumours and those small in size. Chemotherapy alone can be effective for cancers such as haematological neoplasms, for example leukaemia and lymphoma (World Health Organization, 2015). Radiotherapy is the use of ionising radiation to prevent tumour proliferation, thus interfering with malignant cell replication, leading to apoptosis. Radiotherapy affects both normal and cancer cells as the normal cells within the path of the radiation beam are also damaged, which leads to side-effects. Radiotherapy can be given using linear accelerators (external beam radiation) or by placing radioactive material into the tissue or into a cavity close to the site of the cancer (brachytherapy). Radioactive isotopes can be administered by either mouth or intravenous injection to carry out investigations or to treat certain cancers. All these techniques can be used to treat cancer curatively or palliatively. The decision to treat curatively or palliatively is reached by taking into account the extent of the disease, the physical and personal circumstances of patients and their wishes. It is often evident at the time of diagnosis that the disease is so extensive that cure might not be possible. Radiotherapy is still useful where cure is no longer possible, especially when patients are experiencing distressing symptoms. The overall doses of radiotherapy used for palliative treatment are lower than those given with curative intent (Kinghorn & Gaines, 2007).

Surgery is used to prevent, detect, treat and palliate cancer. Curative resection is where all obvious tumour is removed, along with a margin of healthy tissue and organs or tissues that are likely sources of micro-invasion of tumour cells. Stephens and Aigner (2009) agree that often surgery is the primary and only treatment necessary to cure a cancer, for example some forms of skin cancer. According to Poston et al. (2009), surgery remains the principal therapeutic modality with the highest rate of cure. Surgery also remains integral to the treatment of the vast majority of the remainder who require multimodal therapy to achieve a cure. Palliative resections are made when curative resections are impossible at operation. In these cases, the cancer which cannot be removed remains in the body. Palliative resections also refer to surgery undertaken for symptom relief. Tumours are categorised as inoperable when they are large, widely disseminated, or in an awkward position which defies removal, as well as if the removal would not result in any improved prognosis for the patient. Surgery could also be used to prevent cancer for instance a prophylactic mastectomy for a woman at risk for breast cancer, stage cancer, for instance a staging laparotomy in Hodgkin's disease, or as an adjunct to chemotherapy to position implantable venous access devices such as chemotherapy ports (Kirkpatrick, 1986). According to Stephens and Aigner (2009), surgery, radiotherapy and chemotherapy may all be used in conjunction to reduce the risk of recurrence in a potentially curable patient. Often surgery alone is not enough to reduce risk.

Chemotherapy is the use of chemical agents that are cytotoxic, aimed at eradicating or reducing the overall population of cancer cells (Kinghorn & Gaines, 2007). The purpose of treating cancer with chemotherapeutic agents is to prevent cancer cells from multiplying, invading, metastasising and ultimately killing the patient (Skeel & Khleif, 2011). These agents primarily exert their effect on cell proliferation. According to Skeel and Khleif (2011), cell multiplication is a characteristic of many normal cells and cancer cells, thus having a toxic effect on normal cells especially those with rapid turnovers, such as those of the bone marrow and mucous membranes.

Chemotherapy agents are classified according to their pharmacologic action and interference with cellular reproduction, thus targeting cancer cells at different stages of the cell cycle. Cell cycle specific agents are active on cells undergoing division in the cell cycles, whilst cell cycle non-specific agents are active on cells in either a dividing or resting phase. The mechanism of action of most chemotherapeutic drugs is the targeting of the cell DNA in some manner (Otto, 2001). According to Skeel and Khleif (2011), chemotherapy agents are cell cycle specific and sometimes, cell cycle phase specific and in some cases, entirely cell cycle nonspecific. Such knowledge may help to predict response to treatment. Chemotherapeutic drugs are also often given in combination, since this enhances the effect of the drugs on the tumour cells kill, thus providing additional benefits not possible with single-drug treatment, such as maximum cell kill and a broader range of coverage of resistant cells. Chemotherapy drugs affect both normal and cancer cells, thus many side-effects are imminent such as myalgia, arthralgia, anorexia, diarrhoea, mucositis, vomiting, pharyngitis, oesophagitis, nausea, alopecia, cardiac toxicity, constipation, neurotoxicity, nephroctoxicity, ototoxicity, fatigue and haematological side-effects of anaemia, neutropenia and thrombocytopenia (Otto, 2001; Langhorne, Fulton & Otto, 2007).

Chemotherapy can be administered by means of various routes: per os or intravenously by either bolus injection or an infusion. Some chemotherapy drugs are administered intramuscularly or subcutaneously after reconstitution. In some instances, chemotherapy can also be administered directly into a body cavity, such as the bladder, or even directly into the liver. Lastly, chemotherapy can also be administered intrathecally in addition to intravenous administration for some types of cancer.

Chemotherapy can be given as an adjuvant, neo-adjuvant and palliative treatment. Adjuvant treatment usually follows surgery and aims to eradicate microscopic cancer cells which may be present but unseen. Neo-adjuvant chemotherapy is used to shrink a tumour before surgery or radiotherapy, whilst palliative chemotherapy is aimed at controlling the growth of

the tumour cells when cure is no longer possible and to relieve pain by shrinking the tumour when nerve compression is present (University of Iowa Hospitals & Clinics, 2014).

2.4 CARING APPROACHES RELATED TO CANCER

2.4.1 Supportive care

According to Zafar et al. (2008), supportive care, also called best supportive care, is the administration of treatment with the intent or aim to maximise quality of life without using anti-cancer drugs. However treatment may include various modalities such as antibiotics, antiemetics, analgesics, pleurodesis, thoracentesis, nutritional support, blood transfusions, and focal external-beam radiation for control of pain, dyspnoea, haemoptysis, or cough. Koedoot et al. (2003) adds that best supportive care is an alternative option to palliative chemotherapy and aims at improving quality of life by the relief of symptoms once they occur. ESMO (2003) defines supportive care as care which aims to optimise the comfort, function and social support of the patients. The emphasis is placed on optimising the quality of life for all patients. Fadul and colleagues (2009) state that supportive care is given to enhance or improve the quality of life of those patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat the symptoms of the disease; psychological, social and spiritual problems related to the disease and its treatment and side-effects caused by treatment of the disease as early as possible.

2.4.2 Palliative care

Palliative care focuses on psychosocial support, the relief of suffering, and closure near the end of life (Lo et al., 1999). According to the World Health Organization (2012), palliative care focuses on families and patients facing the problems associated with life-threatening illness and aims to improve quality of life. According to Johnston and Smith (2005:701), palliative care comprises the following: “provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, intends neither to hasten nor postpone death, integrates the psychological and spiritual aspects of patients care, offers a support system to help patients live as actively as possible until death, offers a support

system to help the family cope during the patients' illness and in their own bereavement, uses a team approach to address the needs of patients and their families, enhances quality of life and positively influences the course of illness". Billings (1998) describes palliative care using phrases such as: focusing on symptom control and support, the holistic care of patients whose disease cannot be cured, interdisciplinary care, coordinated and integrated services, humanistic, accessible care, end-of-life care, comprehensive care, care that is directed to both the patient and family and extends into the period of bereavement, promoting quality of life, assuring physical comfort and assuring psychological and spiritual support.

According to Bruera and Hui (2010), early referral to palliative care can assist in timely diagnosis and treatment of symptoms, provide psychosocial support and counselling and assist in the gradual transition of care. The authors add that the early incorporation of palliative care principles can improve patients' quality of life and minimise the distress of caregivers. The authors also state that a misunderstanding exists that palliative care is only provided at the end of life, when all cancer treatment options have been exhausted. It is important to note that patients do not have to choose between cancer treatment and palliative care.

According to Bruera et al. (2015), there is an overlap between the descriptions or definitions of supportive care and palliative care. Palliative care includes not only hospice care (care for patients at the end-of-life, for example the last six months), but also acute care programmes providing care for patients with advanced diseases. Supportive care is an encompassing term which includes survivorship care services as well as bereavement programmes for patients throughout the cancer journey. Supportive care includes palliative care and it has been found that the terms are often used interchangeably.

Considering the above, the researcher supports the statement of Bruera et al. (2015) that there is an overlap between the definitions of supportive and palliative care, as it seems unclear where the one starts and the other ends.

2.4.3 End-of-life care

End-of-life care is defined by European Society for Medical Oncology (2003) as palliative care when death is imminent. One of the core principles of end-of-life care is respecting the dignity of both the patient and caregivers. Health care professionals need to respect and be sensitive to the patient's and family's wishes, using the most appropriate and applicable

measures that are compatible with patient choices. The relief of pain and other physical symptoms must be of the highest priority. It is also important to recognise that high quality care for the dying person requires high quality care, but also includes services which are family and community based and offer continuity. Another function of doctors and nurses is to advocate for access to therapies which are reasonably expected to improve or enhance the patient's quality of life, as well as provide access to palliative- and hospice services. Conversely, they should also respect the patient's right to refuse treatment, as well as respect the physician's professional responsibility to discontinue treatment when appropriate, considering preferences of both patient and family. Lastly, it is their duty to promote clinical and evidence-based research on the topic of providing care at the end of life.

Nursing practice at the end of life influences the quality of life of the patients' last days. Nurses enable the last days to be peaceful and person-centred, ensuring comfort and guiding the patient and family to closure. End-of-life nursing also requires ongoing self-care of the nurse, which involves giving of oneself to patients, but also receiving from them by learning from their experiences and knowing the person who is dying. The nurse also needs to stay both physically and especially emotionally healthy and is required to be open, honest and show sincere concern for the patient. Grieving is an essential part of self-care and is necessary for emotional well-being. Nurses also need to let go of their personal agendas, goals and aspirations, thus allowing the patient to take the lead during the acceptance stage at the end of life. Lastly, the palliative care nurse needs to replenish and renew herself by exercising, spending time with friends and family, praying and sleeping (Zerwekh, 2006).

2.5 THE USE OF ANTI-CANCER TREATMENT IN PALLIATIVE CARE

Anti-cancer treatment can be given as part of palliative care. Palliative care includes palliative chemotherapy, palliative radiotherapy, as well as supportive care. According to Kinghorn and Gaines (2007), palliative chemotherapy is given to patients with locally advanced or metastatic disease to prolong life, control symptoms or improve quality of life. The aim would be to relieve symptoms while causing minimal side-effects. Palliative chemotherapy refers to treatment given where the effects of the treatment is inadequate to result in major survival benefits, but improves tumour-related symptoms and where the palliation/toxicity trade-off from chemotherapy clearly favours symptom relief (Archer, et al., 1999). Watson et al. (2009) are however of the opinion that palliative chemotherapy is given firstly to maintain or improve quality of life and secondly to improve overall survival. Old and

Swagerty (2007), warn that although the patient's goals are the deciding factor, the patient may have unrealistic or unreasonable expectations and overestimate the benefits of treatment.

According to Watson et al. (2009), the administration of palliative chemotherapy is determined by the patient's fitness according to the ECOG performance scale. Patients with an ECOG performance status of more than two tolerate chemotherapy poorly and chemotherapy is usually contradicted in such instances. The nature of patient symptoms also plays an important role in the decision to administer palliative chemotherapy, since chemotherapy would be given to relieve specific symptoms, such as dyspnoea in a lung cancer patient. Another determining factor for the administration of palliative chemotherapy is the volume of disease and disease site. Large volume diseases at life-threatening sites, such as the liver, usually require urgent chemotherapy since the patients become symptomatic quickly.

The most challenging issue for patients and physicians, according to Kim et al. (2005), is balancing symptom relief against treatment toxicity. Treatment and patient goals need to be reconsidered when the adverse effects of palliative chemotherapy has a negative influence on the patient's performance status. In palliative care, when cure is no longer possible, radiotherapy is used at a lower dose than that of curative treatment for patients experiencing distressing symptoms, for example painful bone metastases and spinal cord compression (Kinghorn and Gaines, 2007).

2.6 THE IMPORTANCE OF SYMPTOM MANAGEMENT IN PALLIATIVE CARE

The assessment and treatment of symptoms are a vital part of palliative care.

The most frequent non-pain symptoms are chronic nausea and vomiting, constipation, anorexia, dyspnoea, delirium and fatigue. Since symptoms are subjective, their expression varies from one patient to the next, depending on the individual's perception or awareness as well as various other factors such as psychosocial issues. While symptoms are addressed individually, patients often have multiple coexisting symptoms. Once the intensity of a symptom has been assessed, it is important to then assess the symptom in question in relation to the other symptoms such as pain, fatigue, appetite, fatigue, anxiety and depression.

According to Regnard and Dean (2010), pain and other symptoms often cause psychological distress, such as anxiety, which usually settles rapidly if the symptom is relieved. The authors agree with Dalal et al. (2006), that symptoms and problems are often multiple and mixed in advanced cancer.

According to Twycross and Wilcock (2001) and Twycross (2003), various principles apply to symptom management. The principles are evaluation which refers to the diagnosis of each symptom before it is treated followed by an explanation to the patient, management which refers to individualised treatment, monitoring which includes continuing review of the influence of treatment and attention to detail. Evaluation must precede each treatment and should be based on likelihood and pattern recognition.

Important questions need to be asked during the evaluation process which includes the cause of the symptom, the underlying pathological mechanism, what has been tried and failed and how the symptom influences the patient's life. The next step of 'explanation' involves explaining the underlying mechanism(s) in simple terms, discussing treatment options with the patient and explaining the treatment to the family. Patient management follows explanation and involves correcting the correctable, non-drug treatment and drug treatment. Once management or treatment has commenced, monitoring follows, which involves the constant process of review since each patient is different and reacts differently to treatment and new symptoms continue to arise. The emphasis placed on attention to detail at every stage during palliative care leads to the ultimate success of palliative care, minimising the suffering of patients. Unwarranted assumptions should thus not be made (Twycross, 2003).

2.7 THE IMPORTANT ROLE OF HOPE IN PALLIATIVE CARE

Snyder et al. (1991) defines hope as a positive motivational state which is based on an interactively derived sense of successful agency, namely goal-directed energy and pathways and planning to meet goals. Stephenson (1991) indicates that hope is associated with meaning and value in life. Hope is a basic human response and essential for life and is implicated as a factor in maintaining and regaining health and accepting illness.

According to Penson et al. (2007), hope is both the anticipation of something positive and the positive acceptance of what is inevitable. The source of hope is often less important than what hope can do for the person. Hopefulness is more than just an emotion since it overlaps

with resilience, strength of social networks, spirituality and learned adaptation. This mind-body connection is important in coping with adverse situations and illness.

Mattioli et al. (2008) found that the patients' level of hope was not affected by the stage of their disease. Those who noted an improvement with treatment, who perceived the cancer treatment to be effective, had higher hope scores than those who noted no improvement. Healthcare professionals have a positive influence by being friendly, listening, being polite, confident and positive, as well as providing information in an honest, compassionate, and respectful manner. Furthermore, nurses and other healthcare providers are encouraged to recognize the importance of hope for patients with cancer. Nursing care involves assessing patients in a holistic manner, enabling them to adapt to their illness and ultimately obtain optimal health. Nurses have the opportunity to contribute to hope by being interpersonally connected and involved when providing compassionate care.

2.8 THE IMPORTANCE OF QUALITY OF LIFE IN PALLIATIVE CARE

According to Drake (2012), quality of life is a notion that is difficult to define due to the subjective nature of the positive and negative aspects of life. Quality of life refers to the ability to enjoy normal life activities, such as shopping, driving, working and entertaining. Calman (1984) states the term "quality of life" goes beyond the impact of treatment and related side-effects and involves the recognition of the patients as individuals as well as a whole person consisting of a mind, body and spirit. Bottomley (2002) states that quality of life can be defined as an individual's general satisfaction with life and general sense of well-being. Calman (1984) agrees by stating that a 'good' quality of life is usually expressed in terms of contentment, satisfaction, fulfilment, happiness and ability to cope. While survival and disease-free survival is important for cancer patients, overall quality of life is fundamental and was perceived as just as important as survival when making treatment decisions. According to Detmat et al. (2002), quality of life is the most important factor considered by patients in deciding whether to continue with palliative chemotherapy. In contrast, patients were willing to accept major limitations in their quality of life for relatively small survival benefits.

2.9 THE IMPORTANCE OF SUPPORT IN PALLIATIVE CARE

A cancer diagnosis and the cancer treatment that follows impairs patients' social and work activities, sleep patterns, management of their home, family and other relationships and sexual activity (Sanson-Fisher et al., 2000). Slevin et al. (1996) state that a cancer diagnosis awakens emotions such as anxiety, fear, depression, anger, helplessness and despair. It can be a time of great emotional distress for the patient and their family and different sources such as family, friends, doctors and nurses all provide different types of support.

Psychological factors are thought to influence the cancer patient's quality of life, such as the availability and perceived adequacy of social support, are thought to influence the cancer patient's quality of life. Social support encompasses different types of support, including functional and structural support. Structural support refers to the existence and establishment of social relations - for example, marital status, friendships and membership of religious or other organisations. Functional support on the other hand, includes instrumental and emotional support and refers to the resources that individuals within a patient's social network provide. For example, emotional support refers to having individuals who are available to listen, provide reassurance, sympathise, and make the patient feel valued and cared for, whereas instrumental support refers to practical support which includes assistance with errands, activities of daily living or with household tasks and transportation to appointments. Generally, more emotional and instrumental support is available to a patient when there is a larger social network. The availability of social support and a greater degree of social integration, such as larger friendship circles and community involvement, are generally associated with better quality of life in patients (Sultan et al., 2004). In addition, instrumental support may be of more value than structural support for patients with cancer as they may need additional help with daily activities due to the accompanying physical limitations.

With the uncertainty and loss of control that comes with the diagnosis of cancer, comes the need for emotional support. Patients need to understand what is happening to them and need the support and reassurance of others (Slevin et al., 1996). Patients who receive consistent and strong emotional support experience less difficulty adjusting over time. Friends and family can help manage patient's fears by allowing them to express their concerns, while health professionals can discuss concerns as well as provide feedback about their experiences. Krishnasamy (1996) states social support has a positive effect on physical health, mental well-being and social functioning and is beneficial to the cancer

patient in adjusting to the stress of the disease. From the diagnosis, the health carer (nurse and doctor) is in the unique position to support the patient.

Cancer does not only affect the patients, but also the well-being of their relatives and their everyday activities. In order for relatives to cope with this new life situation, support the patient and share the burden of illness, they need relevant, accurate information and emotional support. The authors found relatives mostly needed nursing information, medical information and organisational information. Relatives found information about possible experiences of pain, the patient's cancer, treatment and goals of treatment extremely helpful. Relatives not only needed informational support, but also emotional support (Eriksson & Lauri, 2000).

2.10 SUFFERING – AN INHERENT PART OF THE CANCER JOURNEY

Suffering is common across all phases and stages of cancer and is viewed as an inherent part of illness. Suffering is experienced by persons and not merely human bodies, and the challenges it produces threaten the intactness of the whole person. Suffering is described as a loss of control that creates insecurity. It is a personal experience which is accompanied by strong emotions, including sadness, fear, anguish and despair (Ferrell & Coyle, 2008). Kuuppelomaki and Lauri (1998) state that suffering is defined as a dynamic, negative, undesirable experience, most commonly due to physical factors, followed by psychologic factors and finally interpersonal factors.

Unfortunately cancer is associated with suffering because of the caustic effects of cancer treatments. Suffering remains a common response to illness and death, in spite of it being heard, validated and diminished. Furthermore, suffering can be diminished to a certain extent with the provision of excellent physical care and symptom management, combined with psychological, social and spiritual care.

According to White et al. (2004), suffering is caused by unrelieved physical symptoms such as pain and vomiting, fear of the unknown, loss of self, loss of body image, facing mortality, unresolved family dynamics, lack of meaning at the end of life, discontent with situation, general feeling of loss and hopes and aspirations not being fulfilled. Wilson et al. (2007) categorises suffering into difficulties in physical, social, psychological and existential dimensions. Although there is strong association between suffering and physical symptoms, it was also evident that suffering could be experienced without the presence of physical pain.

Although suffering has a multidimensional character, a strong physical component is present for many patients.

Except for the pain, side-effects and complications of cancer treatment, patients may suffer from the effects of the disease. Any threat to their personhood, for example the loss of social or familial roles, effects on appearance and ability to function, spiritual concerns and perception of the future may result in suffering (Blinderman and Cherny, 2005).

Lindholm et al. (2002) state that family or significant others have been found to play a crucial role in a patient's ability to respond to and cope with the pressure of a cancer diagnosis and subsequent treatment. Their experience of suffering is influenced by the nature and the level of intimacy of the relationship with the patient. It was also found that suffering is alleviated if they are allowed to take part in the care of the patient.

2.11 NURSING THE PATIENT IN NEED OF PALLIATIVE CARE

Once diagnosed with cancer, patients look to nurses for understanding and reassurance, as nurses are the human connection in the health care realm (Ferrell & Coyle, 2008). The nurse-patient relationship is viewed as a central part of nursing practice and the cornerstone of good palliative care (Mok & Chiu, 2004). According to Mok and Chiu (2004), the depth and intensity of this nurse-patient relationship makes it a friendship. Such relationships which demonstrate warmth and acceptance restore patients' faith in themselves. When patients feel they can be themselves within this relationship and express their feelings without being judged, they feel satisfied. Trusting and connected relationships are built by the caring actions, attitudes and trustworthiness of the nurse. Through these relationships nurses find meaning in palliative care, which is ultimately necessary to sustain them throughout their involvement in the cancer journey and to sustain hope for the patients and families. Relationships with patients are found to be enriching which involve both giving and receiving.

Johnston and Smith (2005), in a study conducted in Scotland, found that for patients, expert palliative nursing care consists of effective caring skills and interpersonal skills. Patients expect nurses to meet their needs by 'being there' for them, helping them, providing them with emotional support, provide comfort, being someone to talk to and spend time with them. The nurses in the study were of the opinion they could not provide effective care without, requiring the ability to relieve pain, providing comfort and control distressing symptoms. Johnston and Smith (2005) concur with the expectations of the expectations of the patients by defining the characteristics for an expert palliative care nurse which are: a willingness to

listen, good interpersonal skills, demonstrating an interest in knowing patients as people, being someone the patients feels able to talk to and recognising that some patients may need to feel in control, even when it would appear their state of health does not allow for this.

Georges, Grypdonck and de Casterle (2002) state that palliative care requires that relationships with dying patients and their family members have to be real encounter with a shared mutual understanding. Although nurses develop different levels of relationships with patients in order to manage their own emotional requirements, they found nurses still directed their care to preserving hope, facilitating a peaceful death, easing the struggle, and providing privacy. In addition, nurses felt empowered and satisfied when they experienced reciprocity with patients and perceived their care as meaningful. Skilbeck and Payne (2003) add and agree that the provision of emotional support and care to patients and families experiencing emotional difficulties as a result of physical illness is an important component of palliative care nursing. A relationship exists between the provision of emotional care and support and other nursing activities, such as comfort, touch and enabling others to act for themselves through empowerment. Nurses communicate support during comforting interactions both verbally, through affirming statements, empathy, reassurance, sympathy encouragement and non-verbally, through increasing proximity and touch. These strategies are used to acknowledge patient concerns and create an atmosphere of acceptance to help patients endure experiences of emotional or physical distress.

Communication is one of the most vital aspects of nursing care which ultimately improves the outcomes for patients with cancer and their families. Communication with an optimistic and positive feel was found to be helpful, whereas focusing on the negative aspects was found to be unhelpful and detrimental to the recovery of the patient. Overall, early intervention with emotional support and open communication seems to be very important in caring for patients during palliative care (Skilbeck & Payne, 2003). According to Lyles-Wittenberg, et al. (2013), communication is a powerful therapeutic tool that can empower patients and families with a sense of control. When effective, communication creates an environment of safety, trust and hope in times of crisis; it is central to nursing care and has been found to reduce uncertainty and provide a basis for action.

Although chemotherapy may prolong life by a couple of months, the outcome cannot be guaranteed. According to Audrey et al. (2008), sufficient information must be communicated to enable patients to make informed decisions based on realistic expectations. This should include information regarding benefits of palliative chemotherapy, possible side-effects and adverse events, control of symptoms and survival benefit. Discussions around survival benefit are also found to be helpful to patients who have declined palliative chemotherapy

and enabled them to justify their decision to family members who wanted them to “fight” the disease.

Caring for the patient who is dying is not easy, as nurses encounter much emotional distress and experience feelings of loss when the nurse-patient relationship comes to an end. Creating and sustaining these relationships is recognised as hard emotional work. Nurses describe the effect of the emotional pain endured after the loss of a patient as either being a drain on them or creating a burden (Skilbeck & Payne, 2003).

2.12 SUMMARY

Chapter 2 discussed the literature pertaining to cancer and its treatment. Cancer as a worldwide health problem, management of the cancer patient and caring approaches related to cancer care were presented. In Chapter 3 the research methods with be presented and discussed.

CHAPTER 3

RESEARCH METHODS

3.1 INTRODUCTION

Chapter 2 presented a literature review of the study. In Chapter 3, the research design and methods will be discussed.

Three populations applied to the study, namely the patient, the family and the nurse. The same data gathering and analyses were applicable to all research populations.

3.2 RESEARCH DESIGN

A descriptive qualitative design was selected for the study. According to Brink (2006), qualitative research attempts to understand the phenomenon in its entirety and does not focus on specific concepts only. Burns and Grove (2009) agree with this explanation by indicating that qualitative research is holistic as it seeks to study the whole rather than the portions. In addition, qualitative research is subjective as the researcher plays an active role in the study and influences the findings of the study by means of her values and perceptions. This subjectivity is however needed to understand human experiences.

Descriptive studies focus on the real-life situations and present an accurate account of what exists, presents new meanings and categorises information. According to Sandelowski (2000; 2010), qualitative descriptive studies allow researchers to present a comprehensive summary of the meanings participants ascribe to specific events as it occurs in everyday life. In addition, qualitative description provides findings which are closer to the data as it is less interpretive than other qualitative designs such as phenomenology. A qualitative descriptive design was applicable to this study as the researcher wished to present a descriptive summary of what motivates cancer patients to undergo palliative chemotherapy, what they experience and how the family and nurses caring for them experience palliative chemotherapy.

3.3 STUDY SETTING

The study was conducted in a natural setting. Natural settings are real-life settings which are uncontrolled (Burns & Grove, 2009). The research setting was a private ambulatory cancer care centre in Port Elizabeth. The headquarters of this cancer care consortium is in Cape Town, with various private ambulatory cancer care settings in different parts of Cape Town, as well as coastal towns in the Eastern Cape. Curative as well as palliative cancer treatment and care are offered at these private ambulatory cancer care settings, including both chemotherapy and radiotherapy. The patient population consists mainly of patients who have health insurance. Patients travel from all over the Eastern Cape for treatment, including smaller coastal towns such as Port Alfred, as well as inland such as Graaff-Reinet and Middelburg, with many having a three hour drive to receive treatment. Family members or friends often accompany patients to their doctor's and chemotherapy appointments, lending support. Different health care professionals, including medical and radiation oncologists, medical practitioners, registered nurses, enrolled nurses, radiographers and oncology social workers practice at the various care settings. Most of the health care professionals have been employed by the cancer care centre for at least five years or longer. Patients with different diagnoses are treated at the centre, including those with breast cancer, gynaecological cancers, colorectal cancers, head and neck cancers, leukaemia and lymphomas. The chemotherapy room alone treats, on average, approximately 500 patients per month.

3.3.1 Population and sampling

According to Brink (2006) a population is defined as the entire group of persons or objects that is of interest to the researcher, thus meeting the criteria that the researcher is interested in studying. Wood and Ross-Kerr (2006) agree by stating that a population is everyone who meets the criteria for the people you are interested in studying. Parahoo (2014) defines a population as a number of units, such as individuals from whom data can potentially be collected.

As already mentioned, three populations applied to the study. The patient population consisted of all patients receiving palliative cancer chemotherapy at the private ambulatory cancer care setting in Port Elizabeth. More than 50% of the patients at the private ambulatory cancer care centre receive palliative chemotherapy, and thus data saturation

was the determinant of the number of patients interviewed. Due to the fact that not all patients could be included, inclusion criteria were as follows:

- Older than 18 years.
- Receiving palliative chemotherapy.
- Willing to participate.

The family population consisted of family members, nominated by the patient, who supported the patient during their palliative chemotherapy. To be included in the study, family members had to be:

- Older than 18 years.
- Family member supporting the patient receiving palliative chemotherapy.
- Willing to participate.

The nurse population consisted of all nurses practicing at the private ambulatory cancer care centre, who have cared for patients receiving palliative chemotherapy. The inclusion criteria were:

- Registered or enrolled nurses, employed at the private ambulatory cancer care setting, who have cared for patients receiving palliative chemotherapy at the specific care setting.
- Willing to participate.

Purposive sampling (Brink, 2006) was used to select the three samples. Purposive sampling, a method allowing the researcher to consciously select certain participants, is commonly used in qualitative research as it is a recognised measure to improve the transferability of the findings. According to Sandelowski (2000), purposive sampling is used in qualitative descriptive studies, with the ultimate goal being to obtain participants who are information-rich for the purposes of the study. Purposive sampling was selected for the study as it supports qualitative description and allowed the researcher to include participants who could share the necessary information in a rich manner.

3.3.2 Recruitment and data gathering

The researcher, a registered oncology nurse who has been practicing in the private ambulatory cancer centre for the last nine years, recruited the participants. Patients who were receiving palliative chemotherapy were approached during their scheduled appointments and invited to participate in the study**.** Eleven patients were recruited and all were willing to participate. The patient participants identified the family members who should be included in the study and they were approached. Unfortunately three of the patient participants' husbands were working and living out of town and were not available at the time of the interview. Three of the patients' husbands and sons both participated in the study, thus a total of eleven family members were interviewed. Eleven nurses practicing at the private ambulatory cancer centre were approached and interviewed. Five were registered nurses, two were enrolled nurses and four were registered oncology nurses. One participant had less than one year's oncology nursing experience, one had more than 15 years' experience, whilst the experience of the rest ranged between one and 15 years.

The researcher conducted 33 qualitative interviews (Brink, 2006), guided by interview schedules (Addendum D, E and F), to gather the data. According to Brink (2006), qualitative interviews have the characteristics of both structured and unstructured interviews. In addition, qualitative interviews allow a flexible approach to questioning which awards the participants the opportunity for greater spontaneity, which also allows for adaptation of interaction between the researcher and participant. Qualitative description supports the use of qualitative interviews as, according to Sandelowski (2000), the data gathering techniques for qualitative descriptive studies can include open ended interviews which are minimally to moderately structured.

During the first part of the interview, demographic data were gathered and during the second part, various aspects were explored. The interview schedules for each of the populations were pretested during the first interview to ascertain if changes needed to be made to the line of questioning. According to Polit & Beck (2009), pretesting is seen as a trial run to determine whether the research instrument, in this study an interview schedule, is useful in generating the desired information. The first interviews provided rich information and no changes had to be made to the interview schedules. Probes and prompting questions were used to facilitate a detailed description of the participant's experiences and to clarify issues.

Planning for data gathering was as follows:

- The study was peer reviewed and ethics approval was obtained from the University of the Witwatersrand and the ethics committee of Gouws Vennote Ingelyf.
- The researcher, a registered nurse who has specialised in oncology nursing science, gathered the data.
- The researcher practiced as a registered nurse at the private ambulatory oncology centre and was familiar with the surroundings and known to the participants. The researcher purposively selected and recruited eligible participants who were receiving palliative chemotherapy, family members of such patients and nurses practicing at the centre. The study was explained to the selected participants and upon accepting the invitation to participate, an information document (Addendum A, A1, B, B1, C and C1) was given to them, where after written informed consent was obtained. Participants signed a separate consent form for the audio-taping of the interview. All the participants gave permission for audio-taping.

- The interviews were conducted in a private room at the specific cancer care setting during the patient's normal scheduled appointment. The patient and family were interviewed separately. The family members were interviewed at a different time at the cancer care setting. Only the researcher and the participant were present during the interview.

- The nurses caring for the patient receiving palliative chemotherapy were interviewed during working hours, at a different time to that of the patient, usually early in the morning before patients arrived at the private cancer care centre or during lunch time.
  The nurses who were interviewed had all worked in the chemotherapy room and had experience with administering palliative chemotherapy and caring for palliative patients.
- Due to the sensitive nature of the study, emotional distress could have been experienced. The researcher arranged with the oncology social worker, who is part of the multi professional team, to council participants who became emotionally distressed.
- The interviews, on average, were approximately 60 minutes in duration. The interviews were conducted from October 2012 to July 2014. This lengthy period of data gathering was due to the fact that the researcher was a fulltime employee at the

oncology centre, and thus had to conduct interviews during working hours. Interviews had to be scheduled in such a way as to allow for normal workflow to continue. Patient schedules and availability had to be taken into account. Patients were thus interviewed when they were due to receive chemotherapy as not to inconvenience or tire them unnecessarily. The schedules of family members also needed to be taken into account as many of them worked or had other commitments. The transcription and coding of data also took place concurrently as to determine data saturation, thus contributing to the lengthy interview period. It is uncertain if the patient, family or nurse participants discussed the interviews amongst themselves.

3.3.3 Data analysis

Data gathering and analyses were done concurrently. Data saturation determined the sample size for the patient participants and all family members identified by the patient participants were interviewed. All the approached nurses practicing at the private ambulatory cancer centre during the time of the data gathering participated in the interviews. The data was transcribed word for word after the interviews and an Excel spreadsheet was used to record the general information. Each participant was given a pseudonym.

Thematic analysis, the process of compartmentalizing and conceptualising data (Holloway & Wheeler, 2002) was used to analyse the data. Braun and Clarke (2006) define thematic analysis as a method for identifying, analysing and reporting themes or patterns within data. Thematic analysis organises and describes the data set in detail, followed by interpreting various aspects of the research topic.

The process of thematic analysis consists of different phases, namely familiarising oneself with the data through transcription of verbal data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and lastly producing report (Braun and Clarke, 2006). The recorded interviews were transcribed verbatim. The researcher familiarised herself with the data by reading and rereading the transcriptions. Thereafter, initial codes were generated, followed by searching for themes within the data. The identified themes were reviewed several times before they were defined and named. Lastly, the research findings were discussed in the research report.

The researcher used reflexivity to become self-aware of who she is and was and for the relationship between herself and the research environment in order to produce a more accurate analysis of the research. According to Dowling (2006), reflexivity is a concept central to qualitative research, viewed as a means of adding credibility, by requiring the

researcher to accept itself as authentic in its effort to tell the truth. It also acknowledges that the researcher is involved in both the process and product of the research project. It involves being aware of what is influencing the researcher's internal and external responses, whilst simultaneously being aware of the researcher's relationship to the research topic and the participants. Pillow (2003) adds that reflexivity involves an ongoing self-awareness during the research process. It thus aids in making visible the practice and construction of knowledge within research.

3.4 TRUSTWORTHINESS

Trustworthiness established the rigor of the study. Trustworthiness, or rigor, is what persuades others that the findings reported were worth paying attention to as it is credible, dependable, confirmable and transferable to other situations (Tappen, 2011). Trustworthiness of the findings was promoted according to the strategies Lincoln and Guba and summarised by Shenton (2004), namely credibility, transferability, dependability and confirmability.

Credibility is the qualitative researcher's equivalent to internal validity, asking the question, thus establishing if the findings are congruent with reality. Transferability refers to the extent to which the findings of one study can be applied to other situations, or the wider population. However, the findings of qualitative studies are usually specific to a small number of environments or individuals, therefore it is impossible to demonstrate that the findings and conclusions are applicable to other situations and populations. Dependability or reliability is closely related to credibility. In order to address the issue of dependability, the processes within the study were reported in detail, enabling a future researcher to repeat the work and thus using the research design as a prototype (Shenton, 2004). In order for the reader to have a full understanding of the research method and its effectiveness, a description of what was planned and executed on strategic level, as well as operation detail of data gathering, were included in the text.

Confirmability is the qualitative researcher's equivalent to objectivity and involves ensuring the findings are the results of the experiences and ideas of the participants and not the characteristics and preferences of the researcher (Shenton, 2004). Before the study was conducted, credibility was promoted by an early familiarity with the culture of the participating organisation, as the researcher practiced as an oncology nurse at the site of data gathering prior to and during the gathering of the data. In addition, a research proposal, adapting a well-known research method, was developed and subjected to peer review by the

participating organisation, as well as the University of the Witwatersrand. The research proposal contained an in-depth methodological description allowing for scrutiny of the research results thus enhancing confirmability. During the recruitment phase, confirmability was enhanced by giving participants the opportunity to decline to participate in the study, so that only those willing to offer data freely and honestly could be included. Using probes to elicit detailed data improved confirmability during the data gathering phase.

Transferability was enhanced by presenting a detailed description of the context, the number of participants, data gathering methods and limitations when writing the research report. In addition, dependability was enhanced by giving a detailed explanation of the research design and implementation of the methods.

With regard to credibility, the researcher made provisions to promote confidence that she had accurately recorded the phenomenon. The principle of triangulation was applied. In order to validate the findings and ensure credibility, different people (patients, family members and nurses) were interviewed and the data was also analysed by an independent coder. Tactics to help ensure honesty in informants were applied. The researcher reviewed the patient's history prior to the interview, as well as used the interview schedule to guide the interview and keep the patient on track. Patient folders were available for use to all professional and administrative personnel at the oncology centre. The information obtained from these files was and will not be made known to anyone outside of this centre.

Since the findings of a qualitative study are specific to the particular private cancer care centre and patients, it might not be possible to demonstrate that the findings and conclusions are applicable to other situations and populations – thus transferability. The researcher has therefore provided sufficient contextual information about the private cancer care centre, in order for the reader to understand the data provided, in the context it was intended.

3.5 ETHICAL CONSIDERATIONS

The ethical principles outlined by Brink (2006) were applicable.

- Informed consent was obtained before participation in the study. The participant had the right to decide voluntarily whether to participate in the study (Addendum A, A1, B, B1, C, and C1). Due to the qualitative nature of the study, it was only be possible for the participant to withdraw from the study before the data analysis phase. Once the data had been analysed and synthesised, individual participant's information could not be extrapolated from the grouped thematic analysis.

- Although the participant's name was used in the interview, the name was removed when the data was transcribed and the transcriptions numbered sequentially. The demographic data sheets were numbered sequentially and no name appeared on these sheets.
- No harm was intended. Due to the sensitive nature of study, emotional discomfort might be experienced. No specific measures were to be taken to prevent emotional discomfort except that an oncology nurse, known to the participants, conducted the interviews. When emotional discomfort was experienced by the participant, they were referred to the oncology social worker on site for counselling.
- Patient participants might experience physical discomfort during the interview due to the extent of their disease and or treatment. Should the participant experience fatigue or any other side effect, such as nausea and vomiting, at any time during the interview, the interview would be re-scheduled. The specific physical need of the participant would be dealt with immediately as the standard nursing intervention would be applied.
- Privacy was ensured by interviewing the participant in a private room with only the researcher present.
- All participants who met the criteria of the research population were approached. Data was only gathered until saturated.
- Ethical approval was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (Addendum H), as well as the Ethics Committee of the private ambulatory cancer care setting (Addendum I).

3.6 SUMMARY

Chapter 3 discussed the research methods. The research design, study setting, population and sampling, recruitment and data gathering, data analysis, trustworthiness and ethical considerations were presented. In Chapter 4, the findings of the research will be presented and discussed.

CHAPTER 4

FINDINGS AND DISCUSSION OF THE FINDINGS

4.1 INTRODUCTION

In Chapter 3, the research methods and design were discussed. Chapter 4 will present and discuss the findings of the study. The demographic data will first be presented, followed by a short history of each of the participants and the themes and categories arising from the data.

4.2 THE SAMPLE

The sample size consisted of 33 participants (n = 33) in total. Eleven patients, receiving palliative chemotherapy at the private ambulatory cancer care setting in Port Elizabeth, were interviewed, as well as 11 family members of patients receiving palliative chemotherapy. Three patients' family members were approached, but were unable to attend the interviews due to work commitments out of town. Eleven nurses, nine registered and two enrolled practicing at the private ambulatory cancer care setting in Port Elizabeth, were interviewed for this study.

4.3 THE PATIENTS

4.3.1 General information

As already mentioned, 11 patients were interviewed; two males and nine females. The average age of the participants was 60 and ranged between 40 and 79. Participants were diagnosed with various cancers: four patients were diagnosed with colorectal cancer, two with breast cancer, and the others with uterine cancer, pancreatic cancer, ovarian cancer, lung cancer and cancer of an unknown primary, respectively. Three of the participants were still fully active with an ECOG performance status (PS) of 0. Six of the participants interviewed had a PS of 1, indicating that some fatigue was experienced, but they were still able to perform activities of daily living, such as working outside of the home. Two of the participants had a PS of 2 and were only able to do light work. Patient employment status and clinical information pertaining to the progression of their disease was gathered from

patient files. The number of interviews were determined by data saturation. All patient participants were approached at the start of the study.

A short history will introduce the participants; pseudonyms are used.

Elizah: Elizah was a 52 year old business woman living with advanced breast cancer. She was married and had adult children living away from home. Elizah was diagnosed with breast cancer in 2008. After her initial adjuvant chemotherapy, Elizah's disease progressed and liver and brain metastasis were diagnosed. Following further surgery and chemotherapy, bone metastasis were diagnosed and treated with more chemotherapy. At the time of the interview she was active, managing her own business and able to continue most of her normal pre-disease activities with only mild fatigue but unable to engage in physically strenuous activities.

Mike: Mike was a 63 year old man with advanced colon cancer. He was married and had adult children living away from home. He was a retired branch manager at the time of diagnosis. Mike was diagnosed with colon cancer in 2011. He had liver and lung metastases and was being treated with third line chemotherapy at the time of the interview. Mike was still active and able to continue with all activities of daily living, although he tired easily. He was no longer able to carry out any physically strenuous activities.

Julia: Julia was a 67 year old retired hairdresser living with advanced cancer of the pancreas. Julia was married and the couple had two children living in Johannesburg and Australia respectively. Julia was diagnosed four years previously and was receiving chemotherapy on an ad hoc basis. Treatment was given according to the outcome of her scans, i.e. treatment was given when there was disease progression. At the time of the interview Julia was capable of self-care activities and was up and about for more than 50% of the day.

Frieda: Frieda was a 44 year old woman with advanced rectal cancer. She was married and had two young children, age 12 and 14. At the time of diagnosis in 2009, Frieda was working as a registered nurse at a local private hospital. At the time of the interview, Frieda was being treated with second line chemotherapy after a recent recurrence and was on temporary disability leave. Frieda was ambulatory, but unable to carry out any strenuous physical activity due to fatigue thus unable to work.

Regina: Regina was a 62 year old woman with advanced breast cancer. She was diagnosed in 1999, at which time she was employed as a senior clerk at the local municipality. At the time of the interview she was retired. Regina was married and had adult

children living away from home, as well as an 18 year old daughter who still lived at home. At the time of the interview, Regina was still fully active and carrying out all pre-disease activities without any restrictions.

Oprah: Oprah was a 54 year old attorney who was diagnosed with cancer in 2010. The primary was of unknown origin and she had lung and liver metastases. Oprah was married and lived with her mother and 12 year old daughter. Her husband lived and worked in another part of the country. At the time of the interview, Oprah was being treated with third line chemotherapy. She was still active and able to carry out light work. She was unable to perform any strenuous activities due to fatigue.

Sally: Sally was a 64 year old retired secretary living with advanced ovarian cancer. She was married with two adult sons living in Port Elizabeth and Cape Town respectively. Sally was diagnosed in 2008 and had received various courses of chemotherapy. At the time of the interview, Sally was still active and able to carry out work of a light nature, for instance light housework. She was unable to perform any strenuous activities.

Adolf: Adolf was a 76 year old retired assistant registrar. He was diagnosed with advanced lung cancer in 2013. Adolf was married with adult children living in the surrounding Port Elizabeth area. At the time of the interview, Adolf had been treated with radiotherapy and was currently receiving second line chemotherapy. He was able to perform self-care activities, but was severely fatigued. He was up and about for about 50% of his waking hours.

Angelina: Angelina was a 60 year old retired insurance underwriter. She was married with adult children living in Port Elizabeth. Angelina was diagnosed with advanced rectal cancer in 2013. At the time of diagnosis, Angelina and her family decided to try alternative medication instead of chemotherapy. When she returned for follow-up, her disease had progressed and she experienced severe pain and fatigue. At the time of the interview she was receiving first line chemotherapy. Angelina was fully active and able to carry out all pre-disease activities without restrictions at the time of the interview.

Kate: Kate was a 53 year old manageress living with metastatic colon cancer. She was married with two adult children, of whom the youngest was still living at home. Kate was diagnosed in 2013 and was receiving second line chemotherapy at the time of the interview. Kate was fully active and able to carry out all pre-disease activities without any restrictions. At the time of the interview she was working fulltime.

Sannie: Sannie was a 63 year old woman living with advanced uterine cancer. She was a qualified teacher and, although retired, she was assisting at the school where she previously taught. Sannie was married with adult children living away from home. At the time of the interview Sannie was receiving second line chemotherapy. She was still active, but only able to carry out light work due to chemotherapy related fatigue.

4.3.2 Themes and categories arising from the data

Three themes arose from the data: The hope and decision: *"I want to live longer;"* The good and the bad: *"Fatigue is the biggest stumbling block;"* The sources of support, God, the family and others: *"It makes me feel normal."*

Theme 1: The hope and decision: *"I want to live longer"*

The participants were in agreement about having been informed that the palliative chemotherapy they would receive could not cure them. However, being able to receive palliative chemotherapy gave them hope. Participants hoped the chemotherapy would stunt the growth of the cancer and something might "come up" and they would still be cured. In addition, they hoped to live a longer life, hoped for well-being and that all would end well.

Julia said: *"… he never said there would be a cure… he said we could maintain it…the chemo is to main …to keep under control this is one way of keeping it under control…I think we always have that little ray of hope. You never know…tomorrow something else may come up… there might be a cure a few months down the line… they are doing all these research and things like that. So you always live with that little bit of hope…so, it is fine with me to have chemo as long as I can…"*

Kate said: *"I am positive…although my cancer is not curable, although it's only treatable….I believe there's still hope for every one of us…deep inside I feel as if I have another chance to live life to its full…I have been given a life life…if I don't take it, I will be very stupid…even if it is only for a limited time…one has to accept every lifeline coming in your direction…"*

Adolph added*:"…I look into the future and I want to continue with my life…if it is possible…that is why I said yes (for the chemotherapy)…anything that can help a little…At least still breathe…that is why I said yes…anything…"*

Participants were of the opinion that the chemotherapy "*bought*" them additional time "*to sort out their lives*" and make sure that whatever still needed to be done, was done. Having additional time was a bonus and a blessing to most. Some also believed that if it was not for the chemotherapy, they would "*not have been here today."*

Julia said: *"…every day that you get it is a blessing…"*

Mike said: *"…The main reason for having chemo?… ja…just to give you some time to…you know, once you've accepted the that you're terminal…just to give yourself time to sort your life out. This is basically what we've done…we've had some issues with the kids, that sort of things…getting the house sold…got the house sold, money is invested, my wife will be all right when I'm gone…that was the main thing…"*

Angelina explained: *"It was really the scariest thing of my life…chemo…I always said no ways…I'm not doing it…after trying the natural way, I had to have the chemo…I don't think I'll be cured as such, it might stagnate …I think the main thing is to buy time…definitely."*

Sally said:*"… a friend and I said that if we were ever diagnosed with cancer we would never have chemo…the minute that I heard I have cancer you change your mind very quickly…if it wasn't for chemo I don't know if I'd be here today…."*

Participant's hope to spend additional time with their families motivated them to consent to palliative chemotherapy. Some were of the opinion they were "doing this for my family." They felt their family members needed them and they could still fulfil their roles of partners, parents and grandparents.

Oprah explained: *"I know that I have a terminal disease, but I also know that my child is only 12 years old…you know, I had her late in life…everything revolves around that…it is actually only about her…I still need to prepare her for life…I cannot rely on my husband…he is very rude…he is really very rude…if I have to slip away at this stage, it would be very difficult for her…so this is my reason…I don't care about myself…if I did not have a child having additional days would not have bothered me because I am ready to go…each day the doctor can scratch out for me is a bonus…"*

Frieda added: *"Obviously yes, I do it for the family…I need to be a mother…I must be a housewife…I must be my husband's partner… and I am still there for my kids…chemo can maybe not kill me, but cancer can…"*

Kate said:*"…you know, I am positive…I know cancer is only treatable...there is too much to live for…my children is still there, my grandchildren my husband is still there…I still have something to offer people…"*

Some participants did not consider others in their decision to have palliative chemotherapy, but chose it for themselves. Frieda explained:

"…I do it for myself firstly…I still see it as a second opportunity… this is how I feel, a second opportunity…it is a second chance in life…this is how I see it and if it is a second chance, then I must go for it…"

None of the patients were of the opinion that their family members exerted any pressure on them to have palliative chemotherapy. Mike said:*"…no one said that I had to take chemo…there has been no pressure…it's been basically my decision…even my wife said I must do what's best for me…"*

Adolph added:*"…No, nobody…not at all…this was my own decision…my own decision…indeed a lot of encouragement and positive contributions from my family…"*

Regina explained:*"…no, no…I made the decision…you know…my little daughter wants me to live forever…"*

One participant's family members were the reason for her refusing palliative chemotherapy initially. Angelina said:

"….No, family (decided)…especially my son…he's done so much research. The Sunday before I was supposed to start chemo the first time….we were sitting outside and they both said that they wanted to talk to me… both didn't want me to have chemo. I always said…all my life….that I would never want chemo. They felt I was too thin to have chemo and wouldn't be able to forgive themselves if anything should happen to me while I was having chemo. They wanted me to go the alternative route. So we went to see what the alternative route was all about…"

Most participants were not prepared to stop palliative chemotherapy and wanted to continue as they wanted their health to improve and needed all the chances they could get. Angelina said: *"For as long as it helps…no...there is nothing that would make me stop… I just want to see progress. As long as I'm feeling well, gaining weight…"*

Kate was of the opinion that even if her quality of life should deteriorate, she would still continue treatment. She said: *"I believe that I will take any chance that I get….I like challenges. Even if I have to stay on chemo for the rest of my life….I have accepted that. Up till now it has only been good for me and my family."*

Sally said: *"If it made me very, very sick again… and I felt it wasn't worth it. But I don't know if I'd give it up? I'm a very positive person…"*

Adolf was prepared to stop palliative chemotherapy on the oncologist's advice. He said*: "I would stop if the doctor tells me to stop. When my pain and fatigue becomes worse on chemotherapy I would discuss it with the doctor and accept it if there was nothing more that could be done."*

Theme 2: The good and the bad: *"Fatigue is the biggest stumbling block"*

Some participants experienced pain and discomfort before commencing palliative chemotherapy. Most participants were of the opinion the treatment helped for the pain and reported they experienced *"pain relief"* and *"relief from discomfort.*" Angelina explained:*"…Yes, I had pain before starting with the chemotherapy… I couldn't sleep or sit properly. But now, since the chemo, it's gone… absolutely…"*

Frieda added:*"…I had pain for two months…there were times that I thought I couldn't go on…the first session and it was gone…the pain troubling me for two to three months were gone…I could not believe it…I do not take any pain killers…it was only yesterday…I cannot remember when last did I take a pain killer…"*

In addition to pain, participants experienced other symptoms, such as dyspnoea, nausea and vomiting, which were also relieved by the treatment. Kate said: *"you know, I had…my symptoms were severe stomach ache, nausea and vomiting…that I don't have anymore…so, for me this is positive."*

Oprah explained: *"…the treatment helps…it is not nice to be so breathless…it is not nice to feel that you cannot breathe…that you are going to die right now…you see, I say I am ready to die, to go…but I do not want to die from suffocation…I don't want to struggle to die…and the treatment is definitely helping for this…it really helps..."*

Unfortunately the palliative chemotherapy did not only have a positive influence, it resulted in fatigue which was the "biggest stumbling block" for most of the participants. The fatigue was so severe for some, they wondered whether the treatment was worthwhile. Oprah said*: "…at some stage the tiredness has been a problem…it was really bad being in bed more than anything else…it is not how I am, how I used to be…my entire life I used to sleep four hours per day...that was more than enough for me…"*

Sally explained: *"…it hasn't been too bad, except for the lack of energy last week…I had no energy…couldn't make the bed, couldn't cook, was tired after showering… that's when I thought…is it worth it?"*

Julia said: *"Maybe the third, fourth day I feel a bit tired. But your body tells you to slow down…then I take it easy…sit and read. When I can do my cooking I go do that in the kitchen…but I don't overdo things. It's mostly manageable."*

In addition to fatigue, some participants experienced severe constipation. Similar to the fatigue, participants questioned the worth of living any further. Mike said*:"…basically dreading the side effects…the constipation is really bad…you get a hellavu cramp….is it a live one?...the one night I sat on the loo in tears for two hours…couldn't move…that night I was saying…Lord take me now, I've had enough…"*

Adolf added: *"Oh yes….constipation…it's still very bad and I have to use something all the time… yes, the constipation and fatigue are the worst of the side-effects…"*

Some participants had diarrhoea, which was not as common or severe as the constipation, but still worth mentioning. Oprah said: *"I got diarrhoea at times…but not badly…about four times per day, and then it was over..."*

The chemotherapy also resulted in nausea and vomiting, mucositis and feeling unwell. Sannie shared the following: *"With my first lot of chemo I was terribly nauseous…but the second time around it was different…with the current chemo…I was only very nauseous…I don't feel sick at this stage…I am not scared of tomorrows one (chemotherapy)…tomorrows is a small one…I am scared of next week…I am scared..."*

Oprah said: *"…the chemo tablets…I got those sores in my mouth…it wasn't very nice…"*

Frieda added: *"…that awful feeling man…I eat now what I feel like eating that day… each day I prepare what I feel like eating…that keeps that feeling at bay…that is my downfall…that awful feeling …I am not nauseas, just uncomfortable on my stomach…awful man…"*

Despite the side-effects of palliative chemotherapy, participants found the treatment improved their quality of life. Additionally, some were of the opinion that *"quality is better than quantity".* Mike said: *"I'll put up with the side effects of chemo, as longs as its working. I still say quality of life is better than quantity…If I've got six months left feeling like a human being….and eight months left on chemo…I'd rather take the six than the eight."*

Angelina said: *"…yes, definitely…my quality of life improved…I actually feel like a different person…there's a happy feeling within me…there's nothing bugging me. I feel fantastic. I don't feel like I have cancer….I don't have any pain. I can't say anything negative about chemo…"*

Sally added*:"…I have palliative chemotherapy to extend my life and it has given me quality of life…I think as long as I can have chemo I'll have it. If it's helping me I'm quite willing to cope with it."*

Theme 3: The sources of support, God, the family and others: *"It makes me feel normal"*

God played an important role in the lives of the participants and for some was a source of strength and hope. God was also seen as the One Being who predetermines lives, the One in control, the One with the life plan using cancer to allow them to touch the lives of others.

Kate said: *"I have a lot of faith in The Man Above. I believe that He will give me enough strength so that I can live a full life… my diagnosis is a part of God's plan so that I can reach out to others and touch their lives..."*

Mike said *"….we prayed about it, we've got a lot of faith. It's not for the doctors or the boffins to tell us when…then Lord will tell us when I'm ready to go. He will take me when I'm ready. It's all pre-planned…"*

Sannie added: *"…we always try to put God first in our lives. So we feel this comes from Him. When the medical aid approved the new chemo I felt that it was God saying 'carry on'."*

Being able to visit the oncology centre served as a source of support to participants. Not only did the staff make participants *"feel important, as if they mattered"* but other patients also supported them. In addition, the warmth the staff portrayed motivated patients to come the centre.

Kate said: *"…it helps us so that we don't feel or become negative. You help us until you can't anymore…until we reach the end of the road…the other patients in the chemo are also very supportive…everyone is in the same boat."*

Julia explained: *"…I look forward to coming here…that's honest….everybody is so good…I know this is worth it…"*

Adolf said: *"Coming to the oncology centre is a positive experience, if it was a cold, formal atmosphere, I would've thought twice about coming here. But it is nice coming here."*

Some participants were well supported by their families and even people they came to know of their life situation. The people provided emotional and instrumental support. Maintaining a positive attitude and motivating participants to continue with their lives gave them strength to continue.

Sannie said: *"I have a wonderful husband and children…they stand by me, stay positive…they would never let me think negatively…according to them I am going to live until I'm a 120 years old! This helps me a lot. My husband makes sure that I eat the right stuff… My children remind me every day to carry on…it's nearly over... When I wanted to give up not so long ago and wondered if it was all worth it, my son said 'off course it is…what nonsense is this!..."*

Frieda added: *"My husband told me the other day that I should get out of my pyjamas and put on some clothes…he said I had to get dressed and get out a bit…my husband tells everyone that I'm all right and that things are going well…it makes me feel normal."*

Kate said: *"My support network is very big. People whom I don't even know are touched by this...they come to me and say how well I look…I sometimes just need space and quiet time…my family gives this to me…and when I need to talk, they are there for me."*

Participants agreed that palliative chemotherapy gave them hope; some still hoped to be cured, others hoped to have time to do what remained to be done, whilst others wished for additional time with their families. The decision to undergo palliative chemotherapy was both family and self-driven. The palliative chemotherapy relieved various symptoms the participants experienced, especially pain. Unfortunately the chemotherapy also caused side effects that made the participants wonder whether the treatment was worthwhile. However, despite this suffering, participants were not willing to stop the treatment. Their belief in God provided comfort and hope and the support they received from their families gave them the

courage to go on. The cancer care setting was a safe haven where love and support was provided – not only by the staff but also by other patients.

4.4 THE FAMILY

4.4.1 General information

As mentioned, 11 family members were interviewed; nine males and two females. The average age of the participants was 50 and ranged between 20 and 79; six participants were husbands, two were wives and three were sons of the patients; all were either working or retired. During the course of the interviews, only one family member was in need of referral to the oncology social worker. A short history will introduce the participants - pseudonyms are used.

John: John was a 65 year old British citizen married to Elizah. He assisted Elizah with her business venture and also had his own business to manage. The couple had adult children living away from home and so were living alone.

Sophie : Sophie was a 61 year old female married to Mike. She worked as a secretary. The couple's children lived in other parts of the country.

Leonardo: Leonardo was a 70 year old retired man married to Julia. Although he had interests outside the home, the fact he was retired allowed him to care for Julia as her illness progressed. The couple lived alone as their children were married with their own families.

Henry: Henry was a 67 year old retired man married to Sally. Although retired, he still helped out as a handyman for local contractors. The couple lived alone and were supported by their son, Charles, who lived nearby.

Charles: Charles was a 37 year old man, the son of Sally. Charles and his wife lived in the same city as his mother (the patient participant). He had his own business and was always available to accompany his mother to her chemotherapy appointments.

Margaret: Margaret was a 75 year old retired teacher married to Adolf. The couple lived alone. Both their children were married with their own families, but available to help as needed. Margaret cared for Adolf without assistance from other people.

Brett: Brett was a 62 year old man married to Angelina. Brett had recently retired and was by Angelina's side throughout her diagnosis and treatment. The couple lived alone with their three married children and their families close by.

Tom: Tom was a 33 year old man, son of Angelina the patient participant. Tom worked in the financial sector and was married with three young children.

Liam: Liam was a 54 year old man married to Kate, the patient participant. He worked for an agricultural company. Kate and Liam shared their home with their adult son, Bill. Their adult daughter lived close by.

Bill: Bill was a 27 year old man, son of Kate the patient participant. He was living with his parents at the time of interview. He worked for a small company in the town where they lived.

Piet: Piet was a 60 year old man working part time. He was married to Sannie. The couple lived alone as their married children lived in other cities in South Africa.

The relationships between the patient participants and family members are summarised in Table 4.1:

Table 4.1 Relationship between patient and family member

Patient	**Family member**	**Relationship**
Elizah	John	Husband
Mike	Sophie	Wife
Julia	Leonardo	Husband
Frieda	Not available	
Regina	Not available	
Oprah	Not available	
Sally	Henry	Husband
	Charles	Son
Adolf	Margaret	Wife
Angelina	Brett	Husband
	Tom	Son
Kate	Liam	Husband
	Bill	Son
Sannie	Piet	Husband

4.4.2 Themes and categories arising from the data

Three themes arose from the data: Chemotherapy gives hope: *"It is not over yet;"* Sources of support: "*I try to do things for him…;"* Quality of life: *"Making the most of the time we've got."*

Theme 1: Chemotherapy gives hope: *"It is not over yet"*

Family members became hopeful when their relatives were receiving palliative chemotherapy. They were positive the treatment would work and even cure their loved one. They also hoped the treatment would result in a longer life and general well-being, as well as an improved quality of life for the patient. Despite these hopes, families were aware of the limited time and wanted to *"make the most of the time"* they had and *"live each moment as if it's our last…"*

Brett said: *"… I want my wife around for a very long time… as long as her quality of life is good…and she must be in good shape… I made peace with the fact that the chemotherapy would be ongoing for the rest of her life. And that's what we are prepared to do."*

Leonardo said: *"….pancreatic cancer is a death sentence….chemotherapy gives us hope…..we hope that this chemo will do the same as the others….that it will control the cancer, keep it in place so that it doesn't grow any further…buy more time…. We are hoping for another 5 years?"*

Margaret added: *"(I hope)….his life expectancy would be longer….that treatment would buy more time for us to be together….it's not over yet….we realize it's not forever….we try not to be negative….but realistic and positive…We now have time to sort things out. He is teaching me things like balancing the cheque book. We are making practical use of the time that we have gained…"*

Although the family were hoping their loved ones would live longer, it was important to them that they had a good quality of life; *"quality…instead of quantity"* was more important to them.

Margaret said: *"After radiotherapy this (palliative chemotherapy) is the next means of help…to make him more comfortable…to make him better…"*

Tom said: *"Palliative chemotherapy has been a positive experience. It was definitely the right thing to do. She's almost back to her old self…she's got more energy…plays with the kids. She's got a good quality of life. We expect her way of life…lifestyle…must be back to normal as it can be…as much as it can be. Her lifestyle's a little bit different, but no bad in any way."*

Leonardo said: *"Her quality of life has definitely improved…she is full of energy the day after chemo…we hope for a good quality of life near the end. We don't want her to suffer in this time."*

Together with the hope for an improved quality of life, as well as additional time with their loved ones, family members had a positive attitude during this time of treatment, but remained realistic. They also encouraged their loved ones to remain positive, to "*have a positive mind set".*

John said: *"Death is a reality. You don't have to live your death. I don't have to live her death and I don't have to let her live her death. I'm not going to keep on looking for death around the corner…and I'm going to do my best from stopping her from looking around the corner…keep her positive…"*

Brett said: *"We are so positive now…it's a walk in the park now, looking back to where we've come from…her mood is so great and she's lovely to be around…she used to be quite irritable…and her appetite is phenomenal. We are having a good life together now."*

Liam said: *"We are all very positive. We are trying to keep the negative…the cancer…out of the house. Our family is closer now than before…spending more time together…this to me is something positive."*

Hope was the one thing which made it possible for the family to continue with their lives. They were of the opinion that being able to cling onto hope was what carried them through this difficult journey. New treatment options seem to bring more hope.

Margaret's husband Adolf was becoming increasingly breathless following radiotherapy and was due to start palliative chemotherapy. Margaret said:*"…he is becoming increasingly breathless after the radiotherapy…now we have hope again… we hope that this will make him more comfortable…will make him better…"*

Charles said: *"I think from the beginning the hope was always there that it could cure her. It was always a case that we had to do what we had to do…it's added years to her life."*

Tom's mother tried alternative treatment at first which did not succeed. He said: *"A little bit of hope is what you go on. We didn't have an option…and without giving up…let's try chemo and see what happens."*

Theme 2: Sources of support: *"I try to do things for him…"*

Family members were very supportive of the patients' decision to have palliative chemotherapy. Most family members were of the opinion their loved one needed to do what was right for them, but some motivated and even persuaded their family member to have the treatment.

Sophie said: *"I feel that it's just totally up to him whether he wants to do it…I'm not against it at all. I'll never pressurize him to have chemo or to stop...it must be his decision. He had a three month break and then he decided on his own that he wanted to go back onto it. I'm not against the chemo. If he wants to go back on it, then... and if he doesn't want to, I can live with that."*

Piet was of the opinion that it was totally his wife's decision to have palliative chemotherapy. He said: *"It was completely her decision to have chemotherapy. If she decided that she did not want treatment, I would have supported her too. We sat together and she asked me if she should have treatment. I said it is her decision…she must decide if she wants to live."*

In Margaret and Adolf's case it was "a joint decision." They were supportive of each other in the decision to try palliative chemotherapy. Margaret said*: "We prayed about it and decided together…to do what needed to be done."*

Henry persuaded his wife to have the chemotherapy and said: *"I would say that initially she was a little bit reluctant…..but we persuaded her that that's the way to go….I would certainly persuade her to go on with it."*

Brett indicated he was very encouraging and supportive when his wife had to make the decision to have palliative chemotherapy after trying alternative treatments which had failed. He said:

"She was scared of chemo. We sat down as a family saying chemo can't be worse than what she was already going through. We encouraged her to go for it, try one session and see how it goes."

Family members were of the opinion they were very supportive during the time their relatives were receiving palliative chemotherapy. Families were spending more time together, as well as doing things for each other.

Liam said: *"We're spending more time together, which is a positive thing. Previously we would be rushing around and living past each other…now we spend time together. I am involved in a lot of community projects and things at work…now I tell them that I need to be with my wife…it does not bother me that I can't attend to work things…life is short… We talk about it (cancer and treatment) a lot. It's not something that we avoid talking about."*

Piet added: *"I take more of a tough love approach…I have sympathy, but to a point. I try to be the positive force…encouraging her not to lie down and give up…this is my way to get her through this…to support her. I tell her all the time to stay positive. We're supporting her during the tough times…looking after her."*

Most of the family members viewed support, during the time their loved one received palliative chemotherapy, very important. Not only was it important for the family to support the sick person, but to support each other as a family. The family was also supported by their friends, individuals from the community and people they met along their journey. Tom explained:

"Family support is very important. My sister and I have always been very close….but something like this brings you closer. And if you don't have family….what do you have?"

Margaret added*: "I try to do things for him….to make him more comfortable…without him knowing. I have taken over all the files, cheque book and bookwork ….trying to deal with unfinished business…We get so much support from friends. Some of them also have cancer and are busy with treatment. We can ask them for advice…knowledge is wonderful and helps me a lot."*

Bill said: *"There is lots of support for us as a family as well. Everybody is showing an interest. Everyone has a story of someone they know that has or had cancer. They all have something positive to say."*

William said: *"The cancer diagnosis had a positive influence on us as a family. There are so many people from the community that come around and are encouraging. A lot of young people seem to connect with her."*

God was a source of strength for many family members; their faith carrying them through the difficult times. Bill said: *"People say that you have to have open communication with God. It*

is good for us…it makes it easier to talk to Him. Things come across your path that you have to handle as a family…it brings the family closer together."

Sophie said: *"I know we've handed it over to the Lord and we've put all our trust in Him. It's in God's hands…it's up to Him…I just try to be strong for him…all the time. Sometimes we cry together…"*

Theme 3: Quality of life: *"Making the most of the time we've got"*

Most of the family members expected palliative chemotherapy to improve the quality of life of their loved one, that their quality of life *"would be good during the time of having treatment."* Brett said: *"My expectation is quality of life…we must make the most of the time we've got. Live each moment as if it's your last…"*

Family members were of the opinion that the palliative chemotherapy did have a positive influence on the quality of life of the sick person. Some family members believed the treatment did improve the quality of life of their loved one, whilst others were of the opinion that their quality of life was maintained by the treatment. Brett said:

"We haven't seen her looking as good as she is now in months…she's a totally different person…"

Bill said: *"My mother's quality of life is still very good … She still works every day and only rests when she's very tired. She goes about things at a slightly slower pace, but otherwise she hasn't changed."*

Piet said: *"Chemotherapy will improve your quality of life….help you to feel better…will make your death easier…"*

According to family members there were both positive and negative effects of the palliative chemotherapy.

Piet described it as follows: *"While you are getting chemo it make you feel ill, but in the long run it will improve your life."*

Most of the family members found the palliative chemotherapy improved the quality of life of the sick person by reducing their pain. Leonardo said: *"She has quite severe backache and abdominal pain at times. The chemo is controlling the cancer…keeps it in its place so that is*

doesn't grow… I believe the chemo helps for her pain…that's why she looks forward to going for treatment..."

Brett added *"….she is suffering from excruciating abdominal pain, which was where the cancer was lying…and it wasn't getting better, but getting worse. It was difficult seeing what she was going through…the chemo has sorted out that pain… the prolapse and the abdominal pain. It's really reduced her pain by 95%."*

Brett's son Tom agreed and said: *"…the abdominal cramps are less frequent. Body soreness is less."*

According to Sophie her husband wanted to have chemotherapy as he believed this would control his pain. She explained:*"…he didn't want to take anything because he didn't want to take away the pain…he wants to take away what's causing it…he said the pain might be because of the cancer that it growing…"*

Fatigue seemed to be the most prevalent side-effect observed by family members and was described by relatives as feeling *"listless with no energy."* The fatigue forced the sick person to "rest more" and also had a negative influence on their memory and tolerance.

Leonardo said: *"…fatigue is a factor, but better than the alternative…she's learnt to cope by pacing herself. We don't plan things too far ahead of time, since we don't know how she'll feel….if she'll feel tired…"*

Margaret added: *"…my husband can't move around like before. He would get tired halfway to the bathroom and need to rest. He is very tired for a couple of days after chemo and needs to rest more, but I try to encourage him to stay moving…and this also passes."*

John said: *"She would've been sicker without chemo, but she knackered at the end of the day…not a bundle of joy in the evenings. When she has treatment she's tired for the rest of the day. The tiredness also makes her less tolerant and more forgetful."*

In addition to fatigue, family members observed nausea as a major side-effect of palliative chemotherapy. The nausea seemed to be limited to a couple of days after receiving the chemotherapy, yet the origin was unclear to some family members.

Leonardo explained: *"She is nauseous from time to time, but we're not always sure if it is cancer related or chemo related."*

Henry said: *"Yes…she is a bit nauseous…it seems to happen on this new chemo for about two days after chemo…but thereafter things go back to normal…"*

Charles added: *"When she (mother) gets home…she's nauseous and vomits…but I think it's been tolerable."*

For the family, palliative chemotherapy brought hope – hope that the sick person would be more comfortable and even be cured. Palliative chemotherapy was a positive experience for the family as they witnessed an improvement in their family member and also a better quality of life – something they hoped the chemotherapy would result in. The family allowed the patients to choose whether they would like to have the chemotherapy and emphasised the importance of support. Staying positive played an important role in their lives. The family were aware of the positive and negative influences of the chemotherapy; the control of symptoms such as pain, but also other negative side effects - fatigue, nausea and vomiting.

4.5 THE NURSE PARTICIPANTS

4.5.1 General information

As already mentioned, 11 nurses were interviewed; all were female. The average age of these participants was 40 and ranged between 30 and 59. Five were registered as general nurses, two were enrolled nurses and four were registered oncology nurses. One participant had less than one year's oncology nursing experience and one had more than 15 years' experience, whilst the experience of the rest ranged between one and 15 years.

A short history will introduce the participants and once again pseudonyms are used.

Anne: Anne was a 51 year old registered oncology nurse with 16 years' experience in the field of oncology nursing.

Lettie: Lettie was a 32 year old registered oncology nurse. She had 4 years' experience in the field of oncology nursing.

Jessica: Jessica was a 42 year old registered nurse with a general nursing qualification. She had been practicing in the field of oncology nursing for 18 months.

Mary: Mary was a 49 year old enrolled nurse with no formal oncology training. She had been practicing in the field of oncology nursing for 10 years.

Aletta: Aletta was a 51 year old registered oncology nurse with 15 years of experience.

Christina: Christina was a 43 year old registered nurse with no formal oncology training. She had been practicing in the field of oncology nursing for one year.

Jane: Jane was a 44 year old registered nurse with no formal oncology training. She had been practicing in the field on oncology nursing for five years.

Jennifer: Jennifer was a 44 year old enrolled nurse. She had no formal oncology training and had been practicing in the field of oncology nursing for 15 years.

Jill: Jill was a 40 year old registered nurse who had been practicing in the field of oncology nursing for 5 years. She had no formal oncology training.

Kim: Kim was a 42 year old registered nurse. She had been practicing in the field of oncology nursing for 4 years with no formal oncology training.

Sarah: Sarah was a 47 year old registered oncology nurse with 13 years of experience.

Gwyneth: Gwyneth was a 53 year old registered nurse. She had no additional oncology training but had been practicing in the field of oncology nursing for 10 months.

4.5.2 Themes and categories arising from the data

Two themes arose from the data: Clinging to hope: *"They still think there's hope;"* The positive influence of palliative chemotherapy: *"Palliative chemotherapy is a positive experience for me."*

Theme 1: Clinging to hope: *"They still think there's hope"*

Most of the participants were of the opinion that patients were still *"clinging to hope,"* even if it was false hope. These participants felt the patients consented to palliative chemotherapy in the hope they would be cured, have an improved quality of life, symptom relief and more time with their children.

Aletta said: *"With some of the patients you can see that they haven't made peace with the fact that this is the last for them. They still think there's hope, that's why they still come to the chemo room…they're still clinging to hope…they are under the impression…have a misconception, that something will still happen…that they'll be cured."*

Anne added: *"It's something that they can do about the cancer. They understand palliative chemotherapy as something that will help them…they hold onto every last straw to survive."*

Mary said: *"Each patient still grabs at every last straw. Hope is the big thing. There's always hope for another day…patients cannot wait to start treatment…they think everything is going to change…they'll feel better….will be well again…"*

Most of the nurses believed that patients, in spite of being told by the oncologist that the palliative chemotherapy is being given to treat the cancer and not cure it, still believed in miracles and hoped for a cure.

Lettie said: *"Patients expect a lot from palliative chemotherapy…they think if they get chemo they will be cured."*

Anne added: *"A lot of the Christian patients still hope for a cure in spite of being told what palliative chemotherapy means. I don't think they understand or hear what the doctor tells them….maybe they don't want to hear…"*

Some participants believed patients chose palliative chemotherapy because they, like all other human beings, want to live forever. Jane explained: *"I don't think they understand that it's only to prolong their life. There's always the hope that I might be cured. God will cure me…let me try… you never know…miracles might happen…human beings want to live, nobody wants to die. Everyone wants as much time to live life as possible…"*

Christina added: *"We all know we're going to die, but we have stuff to do and don't want to die yet…we're all human and want to live….there's things we want to do…"*

Participants found it was primarily younger people with small children who would consent to palliative chemotherapy, as they believed their symptoms would be relieved and their quality of life improved.

Kim said: *"…clinging to life…trying everything that is on offer to relieve my symptoms and be there for my children…"*

Sarah agreed: *"…patients still have hope…they want to live a little longer if they can. A lot of them still have something to live for…a child that's getting married…wanting to see their grandchildren…"*

Jennifer added: *"…patients want a longer time to spend with their families. There is still a lot of things that they need to deal with….and some aren't willing to give up so quickly…to die yet."*

Some of the nurse participants felt the patients were pressurised by their family members or doctors to consent to palliative chemotherapy. Aletta said: *"They have chemo because the family says…let's try it…we can't give up…"*

Gwyneth said: *"…the patient didn't want chemotherapy…but the family wanted him to have chemo…he knew what the prognosis was…He started chemo and suffered with a lot of pain and nausea. When I look at the older people, I think a lot of them succumb to family pressure because it's the children who want to keep them alive. I've seen a few where it's more the children that want it."*

Mary said*: "I have experience where the patient says no…but the husband and children say yes. Especially the children pressurize the parents…they don't want to let go."*

Jennifer added: "*There is lots of pressure from the families. They pressurize the patient to try something. The more the patient says no…the more the family wants them to keep trying."*

Participants were also of the opinion that patients were often dishonest with the doctor regarding their symptoms or well-being in order to continue with palliative chemotherapy.

Aletta said*: "Yes….they are definitely different in front of the doctor…they try to be perfect during consultation….as if all is going well…but when they get to the oncology sister, it's as if the book opens up and the real situation is made known. They hide things because of fear that the doctor will stop their treatment if they are honest about their symptoms…they are not honest with themselves."*

Lettie said*: "The patients aren't always honest when they see the doctor for follow-up, because the doctor is going to base his decision to continue chemo on what he sees and hears. I think they omit telling the doctor certain things because they are scared that their chemo will be stopped. It is as if they feel they're not going to tell because their treatment will be interrupted."*

Jill agreed: *"….patients sometimes put up a front when they come here…they are actually much sicker at home…but if they look well, then all is well and they can continue treatment."*

Theme 2: The positive influence of palliative chemotherapy: *"Palliative chemotherapy is a positive experience for me"*

The nurse participants stated they experienced patients seemed more positive when the chemotherapy "worked." The quality of life of the patients also seemed to improve. Seeing such improvement had a positive influence on the nurses. Kim explained: *"I feel positive when I see that treatment worked…patients have a better quality of life…can do more. They can to things that they couldn't before they had chemo…it lengthen their lives and improves their quality of life."*

Christina added: *"Palliative chemotherapy is a positive experience for me…most of them have a good quality of life. There are setbacks…but then there's improvement again. And I think some patients gain years…."*

Jennifer explained she had seen sick patients improving on chemotherapy: *"…yes…I've seen a lot of sick patients improving on palliative chemotherapy... it's truly amazing….at least they have a good quality of life for a few months."*

Participants also commented that patients experienced relief of pain when receiving palliative chemotherapy. Gwyneth said: *"The patient had severe pain and the doctor felt that the chemotherapy would help….and it definitely did. After the first chemotherapy session the patient was fine and couldn't believe that it had helped."*

Sarah added: *"I don't know if they know that their symptoms will improve…unless doctor tells them. I do think that they are sometimes amazed when their symptoms do improve, like with bone metastases that improve….when they walk with more ease…"*

Nurse participants were of the opinion that most patients had a positive attitude toward palliative chemotherapy and found this very positive and encouraging. Jane explained patients generally had a positive experience when receiving palliative chemotherapy: *"People are really positive. I chatted to one lady…she said 'I know there's no cure…I'm not going to be cured from this'…but she was happy to continue. Some of them do understand that they won't survive it…but for now it works for them."*

Mary said*: "I find that our patients are very positive. They feel that everything will change …they will feel better….will be well again…"*

Lettie said: *"I think most patients are positive about palliative treatment. They come back…there's a recurrence…a progression... they come back and have more chemotherapy….they keep coming back."*

Although the nurse participants were of the opinion that palliative chemotherapy improved the quality of life of patients, they were quite aware of the side-effects these patients experienced. Fatigue was described as *"the main one,"* whilst nausea and vomiting were not seen as prevalent problems.

Sarah said: "They all complain of fatigue…especially the younger patients who still work and have young children….they can't complete daily tasks...can't cook…can't pay attention to their children…"

Jane added: "….fatigue…not wanting to do anything. More that because nausea and those kinds of things can be controlled…so I think it's more the tiredness…the fatigue, no energy."

Jill said: "These days' people don't complain so much about nausea…but fatigue… It is as if fatigue is overwhelming for most patients…they are extremely tired...and sleep doesn't always help for this."

The nurse participants were of the opinion that patients consenting to palliative chemotherapy were clinging to hope - hope for a better quality of life, symptom control and extra time with their families. However, they believed the patients' hope for a cure or a miracle was false. The nurses believed family members pressurised patients into having palliative chemotherapy and that it wasn't always the patients' choice. In general, the nurses experienced palliative chemotherapy positively especially when seeing an improvement in the patients' quality of life or when pain relief was evident after commencing palliative chemotherapy. The patient's positive attitude encouraged them. Fatigue was highlighted as the major side-effect.

4.6 SUMMARY OF THE FINDINGS

The aim of this summary is to assemble the findings of the three groups interviewed.

Hope was a common thread throughout the interviews - patients hoped for a cure, a longer life, well-being and relief of symptoms. The family members had the same hopes of wanting their relatives to live as long as possible with an improved quality of life. The nurses agreed

that patients were motivated to consent to and continue with palliative chemotherapy by their hope and belief that their families needed them. Palliative chemotherapy's perceived promise of more time motivated both the patients and their families and helped them to continue with lives.

Patients' decisions to undergo palliative chemotherapy were self-driven. However, the families were often the driving force behind the patients' decisions as they persuaded them to consent to and to continue treatment. The nurses experienced this and indicated that patients often had very little say in the decision to undergo palliative chemotherapy. They felt the family was behind it all.

Quality of life was important to all three groups interviewed, patients, family members and nurses. Patients and the families were willing to continue chemotherapy as long as it was of benefit. Improvement in quality of life, as well as symptom relief, was a positive experience for all groups and served as motivation to continue palliative chemotherapy. Many patients and their relatives were reluctant to stop treatment, even when it was evident nothing was being gained by continuing. Palliative chemotherapy was a positive experience for the patients, the families and the nurses.

4.7 DISCUSSION

The study provided evidence that palliative chemotherapy was a positive experience for the patients, family members and nurses. Palliative chemotherapy gave both the patients and family members hope - hope for general well-being, symptom control, improved quality of life and to live longer. In addition, patients and family members hoped this treatment would still be able to cure the sick person. The nurses were quite aware the patients still hoped for a cure and as supported by "*they think if they get chemo they will be cured,"* seemed to be cynical about this – yet palliative chemotherapy was a positive experience for them too. This finding is supported by Slevin (1992), who states the hope treatment brings is part of the benefit patient's gain from palliative chemotherapy. In addition, the current study supports the finding of Mattioli, Repinski & Chappy (2008) that hope assists patients to adapt to and find meaning in illness, maintain a high level of well-being, give direction and a reason for being. Hope motivated patient participants to have and continue palliative chemotherapy. In addition, Penson, et al. (2007) say hope is at the core of many who wrestle with cancer and sustains many patients through dark times. When it becomes clear a person is not going to

survive cancer, there is still hope they will die a good death. It was interesting that none of the patient or family participants mentioned a good death, which could support the nurses' opinion that palliative chemotherapy results in false hope. However, according to Buiting et al. (2013) receiving palliative chemotherapy seems to shift patients' attention away from the approaching last stage of life and help them to live in the present and enjoy the life and time they have left.

As supported by "*It's been basically my decision"* (patient) and "*It was completely her decision,"* both the patients and family members were of the opinion that the patient was the one who made the decision to have palliative chemotherapy. This, however was not the experience of the nurses as they reported various incidences where family members, especially children, exerted pressure on the sick person to have chemotherapy. It was interesting to find the patients made these decisions as, according to de de Kort et al. (2010), studies have shown that not all cancer patients want to take part in the decision making and value the fact they are able to trust their physician. In addition, Grunfeld et al. (2006) are of the opinion that the decision to use palliative chemotherapy is often complex and difficult and that the person who most influences the patient's decision is the oncologist. Whether this was the case in the current study is not clear as neither the patients nor the family members and nurses mentioned the oncologist influencing the decision. Zhang & Siminoff (2003), in a study conducted in the USA, found that as the cancer progressed and treatment outcomes became more uncertain, the disagreements between family members and patients became more frequent. This seems to be in contrast to the findings of the current study, as no disagreements were reported despite the fact the patients had advanced disease and were treated with palliative chemotherapy which offers no guaranteed outcomes.

Although some patients in the current study still hoped for a cure, they wanted additional time with family, to be pain-free and to maintain their lives as they knew at that time. Doyle et al. (2001, when exploring the expectations of palliative chemotherapy in women with ovarian cancer, found a similar trend as more than half (65%) of the women in their study expected chemotherapy to result in a longer life, whilst 42% hoped this treatment would cure them. In addition, the quality of life of these participants improved and was sustained for a median period of two months. According to Kim, Fall & Wang (2005), palliative chemotherapy is aimed at enhancing quality of life. Similarly, the patients, family members and nurses in the current study were of the opinion that palliative chemotherapy improved the quality of life of the sick person. Bang et al. (2005), in a study conducted in Korea, also found the patient's quality of life improved meaningfully when receiving palliative chemotherapy with pain and sleep disturbance improving significantly.

As supported by "*I cannot remember when last did I take a pain killer…,"* the patient participants in the current study reported the chemotherapy relieved their pain, which was supported by the nurse participants. The levels are not known as this was not assessed during the study. However, Geels et al. (2000), in a study conducted in Canada, showed pain improved significantly in response to palliative chemotherapy. Kim, Fall & Wang (2005) states that tumour response to palliative chemotherapy correlates with symptom control, which includes pain control. The authors also mentioned that even without evidence of tumour response, patients benefitted clinically from palliative chemotherapy – for instance patients with pancreatic cancer required less analgesia whilst receiving palliative chemotherapy. Middleton et al. (1998), in a study conducted in the UK, found 62% of the patients in their study had overall improvement of their symptoms, with a particularly good response of pain in 79% of the patients.

It was not unexpected that the patient participants in the current study experienced various chemotherapy related side-effects including fatigue, nausea, diarrhoea, constipation and mucosits. It seemed as if the most common and most debilitating side effect reported by the patients, families and nurses was fatigue. According to Portenoy & Itri (1999), fatigue is a well-known complication of cancer and its treatment and is highly prevalent amongst cancer patients. Fatigue is a major obstacle to maintaining normal daily activities and has a serious adverse effect on quality of life (Vogelzang et al., 1997). Fletchtner & Bottomley (2003) state 75% of patients will report fatigue during or after treatment, which is experienced as a sense of malaise, tiredness, exhaustion or feeling sick. Fatigue also leads to a decrease in activity and thus affects quality of life negatively. Curt et al. (2005), in a study conducted in the USA, found 30% of patients reported fatigue on a daily basis, whilst 54% stated that fatigue lasted the longest of all symptoms experienced, including nausea and pain. In addition, the authors found that fatigue impairs daily functioning which not only leads to negative effects of quality of life, but also has a negative influence on self-care capabilities and the desire to continue treatment. In contrast, patient participants in the current study did not mention fatigue as a possible reason for not continuing chemotherapy.

Both the patients and family members mentioned nausea as one of the major side-effects. For some it was manageable with medication, whilst others suffered from unrelieved nausea as supported by "*I am scared of* [the nausea of] *next week."* It was interesting to find the nurse participants did not mention nausea as a prevalent problem as supported by "*nausea and those kinds of things can be controlled;"* nurses were of the opinion that medication can control the nausea. According to Rhodes and McDaniel (2001), nausea and vomiting are amongst the most common and distressing symptoms cancer patients report and endure. The authors add that nausea and vomiting significantly influence patients daily functioning

and quality of life. Baines (1997) states 50 to 60% of patients with advanced cancer suffer from nausea or vomiting, but adds that nausea is treatable and manageable with oral anti-emetic use. Unfortunately it did not seem as if all the patients in the current study were able to control the nausea. Despite fearing the nausea, patient participants who had unrelieved nausea were prepared to live with it and did not mention this as a reason to stop palliative chemotherapy as they knew it was a temporary side-effect.

Despite the chemotherapy related side-effects the patients in the current study experienced, they wanted the treatment to continue. It seemed as if the benefits of the treatment outweighed the burden of the side-effects. Matsuyama, Reddy & Smith (2006), in a literature review, found patients would choose chemotherapy for a small benefit as side-effects appear to be less of a concern to the terminally ill person than the wish to live longer. In addition, patients' value small benefits greatly and believed that toxicity was less important than small gains or the hope for small gains. According to Kao et al. (2009), patients are willing to endure substantial side-effects for a remote chance at a small prolongation in life.

The study revealed that family members were a source of support to the patients, giving them hope and courage to continue with their lives, illustrated by "*they stand by me…it helps me a lot…"* In addition, the family members supported the patients' decisions to have palliative chemotherapy which could have enhanced the supportive relationships. This finding is underpinned by Mattioli, Repinski & Chappy (2008), who identified family members as a source of hope, adding that love of family and friends' fostered hope. As evident by the current study the patient participants also identified other non-family members serving as support structure for them. The patient participants were also appreciative of the support of the staff at the oncology centre, stating they made them "*feel important, as if they mattered."* Cameron & Wentworth (2014) agree with this these findings by stating that supportive relationships have positive influence on how patients adjust to illness and its treatment, their well-being, experiences of treatment, their coping abilities and quality of life, whilst Matioli, Repinski & Chappy (2008) state that positive encouragement, compassion and support from healthcare providers contributes to hope. As supported by *"They have chemo because the family says…let's try it…we can't give up"* and *"…the patient didn't want chemotherapy…but the family wanted him to have chemo…,"* it was interesting to find nurses were not as appreciative of the role of the families as the patients were, as they believed the families exerted pressure on the patients to undergo palliative chemotherapy. Whether this phenomenon had any influence on the supportive relationships between the patients and families and the nurses and the families is unclear and should be investigated before a conclusion can be made.

The family members on the other hand received support from each other, as well as from friends and acquaintances. The current study also revealed that families became 'closer' along the 'palliative chemotherapy journey,' supporting each other and spending more time together. According to Given, Given & Kozachik (2001), support from health care professionals, family and friends can help family caregivers expand their capacities to respond to care demands, ensuring the patient's comfort and enhancing his or her quality of life. The authors add that support should balance the psychosocial needs of the caregiver and promote the caregiver's physical and emotional well-being so that he or she can more effectively attend to the physical and emotional needs of the patient with advanced cancer.

The study revealed that religion played an important role in the lives of the patients. For some, God was a source of strength and hope. As supported by *"I have a lot of faith in The Man Above. I believe that he will give me enough strength so that I can live a full life…my diagnosis is a part of God's plan so that I can reach out to others and touch their lives…,"* God was also seen as the One Being who predetermines lives, the One in control, the One with the life plan using cancer to allow them to touch the lives of others. According to Moadel et al. (1999), religion promotes adjustment through its ability to give meaning and hope and thus providing an explanation for the experience of illness and suffering. Successful coping is dependent on a sense of meaning which is associated with higher levels of spiritual resources. Balboni et al. (2007), in a study conducted in the US, found religion is important to most advanced cancer patients. An association was made between the support of the patients' spiritual needs and quality of life. Furthermore spiritual support may help patients find their peace with God and thus maintain quality of life by providing them with opportunities to seek spiritual counsel and express spiritual fears. Norum, Risberg & Solberg (2000) agree by stating that religion, or being religious, provided a way to accept, treat and cope with suffering and illness. In addition, Pinto, Berenbuer & Martins (2013), in a study conducted in Portugal, found religious beliefs have an important contribution in promoting wellbeing and the patient's quality of life as religious beliefs can have a significant impact on how a person views the future, with those believing in a higher entity having less fear of the future.

As supported by *"I know we've handed it over to the lord and we've put all our trust in Him. It's in God's hands…it's up to Him…"* the current study also showed that God was a source of strength for many family members; their faith carrying them through the difficult times. Lin & Bauer-Wu (2003) state having faith, such as knowing God, was important for having a

sense of hope. The authors add that a connection to God brings strength and helps to sustain individuals.

In the current study, the nurse participants did not reveal much about their views on religion or faith. This could be due to the fact the nurses focused more on the physical and not the existential aspects of the patient's lives.

The nurses' statements *"Yes…they are definitely different in front of the doctor…they try to be perfect during consultation…as if all is going well…They hide things because of fear that the doctor will stop their treatment if they are honest about their symptoms"* and *"The patients aren't always honest when they see the doctor for follow-up…"* underpins the finding that the nurses were of the opinion the patients were not open and honest about their illness experience when talking to the doctor as they feared the chemotherapy would be stopped if the doctor knew the truth about their condition. Neither the patients nor the family members mentioned such possibility. Buiting et al. (2011) state that patients were often more optimistic about their medical condition towards their physician, hoping for further treatment options, since further treatment was interpreted by patients as a sign of hope. Patients would often speak freely with nurses about how they felt and what they feared, but would ask for more treatment when seeing the doctor. Patients would also often behave as if they were ignorant about their poor prognosis and life expectancy. Nappa (2014) found that nurses who worked with patients for a long time had a well-founded knowledge of the patients' performance status and they found patients to be more talkative towards them regarding their deterioration than with their physicians. It seems quite possible the patients portray different messages to the oncologist and the nurses complicating the decision to stop palliative chemotherapy. This is however speculation and needs to be investigated before conclusions can be made.

As supported by *"If chemotherapy affects the quality of life negatively and there's no improvement, then one should stop…"* the nurse participants in this study agreed with Kim et al (2005), that when adverse effects of palliative chemotherapy begin to cause a decline in performance status, treatment should be reconsidered. Buiting et al. (2004) found nurses are more inclined to express their concerns regarding continuation of palliative chemotherapy as they want patients to make the best of the time that is left. Nappa (2014) found nurses were more likely than physicians to question whether further palliative chemotherapy was in the patient's best interest. Continuing chemotherapy beyond the duration, in the best interest of the patient, become an ethical dilemma for nurses when they had to implement treatment and live with it, irrespective of their doubts. Furthermore, Nappa (2014) states that ceasing palliative chemotherapy might be in the patients best interest, in order to avoid

consequences such as increased hospital admissions near the end-of-life. He adds that a major risk for the patient receiving futile, toxic and potentially life-threatening palliative chemotherapy is that of a worsening of quality of life.

Nurse participants, as supported by *"because you don't want to see a person suffering…"* found unrelieved suffering a difficult situation which they struggled with. White et al. (2004) supports this finding by indicating that nurses involved in palliative care encounter suffering. Although suffering is seen as part of human experience, anyone who interacts with the person who is suffering is inevitably drawn into the process. In addition, the impact of unrelieved suffering is exacerbated by the nurses' connection to the patient which becomes a difficult situation that nurses struggle with and often wanted to avoid. According to Ferrell (2006), the most common distress for nurses was the recognition that continuing aggressive treatment was futile and would deny patients of the benefits of palliative care. The authors highlighted that nursing professionals needed support because of their intimate involvement with patients and families. Ferrell & Coyle (2008) state that witnessing suffering is the everyday work of nurses and suffering is part of being human, often intensified when being human also involves being ill. The author's state suffering may include pain, but is not limited to it and the relief of suffering is an obligation of medicine. Nurses are looked to by individuals for reassurance and understanding and are seen as the human connection in the overwhelming reality of health care. Nurses thus play an essential role in reducing the suffering of cancer by the act of comforting as they give voice and a listening presence to the individual's suffering. The relief of suffering is at the core of nurses' work as a profession committed to the human response to illness.

When applying Parse's Theory of Human Becoming to the findings of the study, it became evident that the patient participants were indeed "free agents," choosing freely to undergo palliative chemotherapy. Although the nurses did not have control over the choices of the patients or their families, they were involved in the cancer journey by supporting both patients and family members throughout.

4.8 SUMMARY

Chapter 4 presented and discussed the findings of the study in view of information available in literature. In Chapter 5, the justification and limitations of the study will be discussed and recommendations made for further research.

CHAPTER 5

JUSTIFICATION, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The focus of this chapter is to justify the study in terms of the research purpose. With this final chapter the researcher intends to justify the study in terms of the purpose. In addition, limitations and recommendations are presented, the study will be concluded and the researcher will reflect on her experiences whilst engaged in this study.

5.2 JUSTIFICATION OF THE STUDY

The purpose of the study was to gain insight into what motivates cancer patients treated at the private cancer care centre in Port Elizabeth to undergo palliative chemotherapy and how the patient, family and nurses experience palliative chemotherapy.

As described in Chapter 3, which focuses on the research design and methods, in depth qualitative interviews guided by interview schedules, were conducted with 11 patient participants, 11 family member participants and 11 nurse participants and audio recorded. Interviews were transcribed word for word and thematic analyses analysed the data. As explained in Chapter 4, three patient themes were identified: the hope and decision, the good and the bad and the sources of support. Three family themes were identified namely, chemotherapy gives hope, sources of support and quality of life. Lastly, two nurse themes were identified: clinging to hope and the positive influence of palliative chemotherapy. The findings described what motivated the patients to undergo palliative chemotherapy and also described the experiences of patients, their family members and the nurses who care for them. It can therefore be stated that this study was justified in that the purpose has been achieved.

5.3 LIMITATIONS OF THE STUDY

The study had various limitations. The research was conducted in a private cancer care centre, serving primarily patients who can afford private health care or health insurance. This suggests that patient and family participants may have had more financial resources and access to less challenging health care than those treated in the public sector, which could have influenced the findings of the study. The patient participant selection for the study was completely random. Patients were approached and no note was taken of how many were male or female. Thus the fact that nine of the patient participants were female and two were male is completely coincidental.

The same probes and prompting questions were used for all participants in all populations. Patient participants were asked to tell the researcher about their reasons for undergoing palliative chemotherapy, to share their expectations, experience and the side-effects experienced. Family participants were asked to tell the researcher about their feelings about the patient's decision to have palliative chemotherapy, their expectations and experiences, and the side-effects that they observed. Nurse participants were asked to tell the researcher about their feelings about palliative chemotherapy, their expectations and experiences whilst nursing patients receiving palliative chemotherapy. These general probes lead to more specific questions during each interview as it evolved. Thus although the probes were the same for all participants, the more specific questions were different depending on how the interview evolved.

Another limitation of the study was the fact that no negative perspectives of the family members were documented in the findings. This is most probably due to the fact that the overall culture of the oncology practice is that of hope and positivity.

In addition, the qualitative nature of the work does not allow the application of the findings and conclusions to other situations and populations. No qualitative study reflects the only true meaning, as the narratives can be interpreted in different manners. However, the researcher believes the themes arising from the data are authentic and could be applicable to other patients receiving palliative chemotherapy and their families as well as the nurses caring for them as there could be overlying issues applicable to other patients and their family members and nurses facing the same phase in the cancer trajectory.

5.4 RECOMMENDATIONS FOR FURTHER RESEARCH

To obtain more insight into what motivates patients to undergo palliative chemotherapy, their experiences and the experiences of their families and the nurses caring for them, it is recommend that a similar study is conducted in the public health care sector serving the greatest majority of cancer patients in South Africa. In addition, it could be of value to inform nurses practicing in cancer care settings as to why patients consent to treatment which leads to many side effects but would not cure them, as understanding of what motivates patients and their families would allow nurses to support the patient and family with greater understanding.

5.5 REFLECTION OF EXPERIENCE

Before I commenced this study, administering palliative chemotherapy and caring for patients receiving palliative chemotherapy was a difficult, depressing experience. I never realised palliative chemotherapy, despite having all the side-effects, is hope giving even if the hope is not always realistic.

I discovered that all patients hoped for something, being it a little more time with their families, a little more time to finalise personal affairs, relief of symptoms and so forth. Some even hoped for a cure, in spite of being told a cure was not possible. Mostly, everyone wanted to live longer, whatever their reason, even just a couple of months were worth coping with the side-effects.

Another discovery was that fatigue was the most crippling or debilitating side-effect of palliative chemotherapy and was the one side-effect patients had difficulty coping with. It could not be medicated or alleviated by any form of treatment, it was just something the patient had to live with. Nausea, diarrhoea and pain could be relieved by medication, but not fatigue. It was also heart-warming to hear how supportive the patients' family and friends were, not to mention staff at the oncology centre and fellow patients and how this support encouraged and motivated them to continue their treatment and not give up.

I also experienced that family members were very hopeful, although often more realistic than the patients. They hoped the patient would live longer, but mostly that they would have a good quality of life for the remainder of the time they had left. I found the family members were generally very supportive of the patient's decision to undergo chemotherapy and

basically supported them in whatever decision they made. I realised many of our patients were extremely privileged to have the support of their families and that there were many others who had to travel this journey alone. It saddened me when I thought of other patients who had unsupportive family members who were unwilling to understand and support the decision they made.

The nurse participants seemed to think many of the patients had false hope; hope for a cure or a miracle. I was surprised many of them thought that patients were pressurised by their family members to consent to palliative chemotherapy. In spite of the above, the nurses found caring for these patients to be a positive experience and were encouraged when an improvement in quality of life was evident.

I was often sad during the interviews. Listening to the patients and family members share their feelings and hope for the future was encouraging, but knowing that for many there would not be much time left saddened me. The courage with which the patients and family members embraced the cancer journey was amazing, especially when all parties realised it would be a short journey. The saddest part was probably looking back and remembering the interviews and then realising that some of the participants had passed away.

Before commencing this study I could not understand why patients would want to undergo palliative chemotherapy if they could not be cured or live for an indefinite time. Why would anyone suffer through side-effects if they were going to die anyway? I now know palliative chemotherapy has a place. It improves quality of life, relieves cancer symptoms and prolongs life. Patients and family members gain precious months in which to finalise affairs, say goodbyes and often re-discover their faith. Extra time is gained to spend with loved ones. Nurses who care for these patients have the privilege of getting to know these special people, travel the cancer journey with them and learn valuable life lesson.

5.6 CONCLUSION

The study provided evidence that palliative chemotherapy gave patients and their families hope, hope to live longer and have a better quality of life. Despite experiencing many side effects, of which fatigue was the worst, patients and their families persevered in order to have more time together. Although nurses were of the opinion that patients often had false

hope, they still found that caring for patients receiving palliative chemotherapy was a positive experience, especially when they saw an improvement in the patients' quality of life.

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ADDENDUM A and A[1]

Nursing Education

INFORMATION LEAFLET AND INFORMED CONSENT (PATIENTS)

Title: The need for palliative chemotherapy. A patient,family and nurse perspective.

Dear Patient

My name is Theola Potgieter. I have been practicing at this private ambulatory cancer care centre for 6 years. I would like to invite you to take part in a study I am conducting at the private cancer care centre. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to phone me, Theola Potgieter at 041-363 0581during office hours (08:00 – 17:00), or after hours on 082 327 2045. You should only agree to take part if you are completely satisfied with all the procedures involved.

WHAT IS THE STUDY ALL ABOUT?

The study is about understanding why patients prefer to get palliative chemotherapy, what they expect by choosing this treatment and how they experience the treatment. The study also involves the family and nurses caring for patients receiving palliative chemotherapy as they will also be asked to describe their experiences.

WHAT WILL YOU NEED TO DO IN THE STUDY?

If you would like to join the study, I will first ask you to sign a consent form. This form is to show that you will allow me to interview you and include the information that you give me in a scientific report. Then I would invite you to tell me a little of yourself like how old you are

and where you come from. Then I will ask you to tell me about your sickness and the treatment that you are getting. The interview will take about an hour of your time.

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You have to be a patient at the private ambulatory cancer care centre undergoing palliative chemotherapy. You also need to be older than 18 years.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

You might become sad when you tell me about your illness. Unfortunately this is the only way that I can find out how you experience the treatment, what you expect from it and why you chose to receive it. If you are upset I will be able to refer you to a social worker experienced in counselling oncology patients. Remember that you may decide at any time during the interview that you don't want to be in the study.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

By participating in this study you will help me to find out why patients would like to be treated with palliative chemotherapy, what they expect from this treatment and what they experience when having this treatment. When nurses are able to understand why patients choose palliative treatment it would assist them to educate, advise and support patients receiving palliative chemotherapy better. There are, however, no benefits for you personally and you will not be paid for your participation.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

You can choose if you want to take part in the study. You can also, during the interview, say that you do not want to take part any more. You can even tell me that I cannot use the information after you have talked to me about. Once I have typed what you have said, I will erase your name and nobody will be able to identify your information. Once your name has been erased, I cannot end your participation any more as I also would not know which information is yours and which information has been given to me by another person. Should you decide during the interview that you would like to end you participation, you are perfectly within you rights and your decision will not influence the treatment and care you are receiving at this specific cancer care centre.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED FOR THE STUDY?

What you say to me is confidential and only the researcher (myself) would be able have access to your information. I will not identify you in any way on my records – your information will be given a code number which cannot be traced back to your name. When I type what you said, I will remove your name and your name will not be used when we write the report.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Before asking you to take part in the study, the Human Research Ethics Committee (Medical) of the University of the Witwatersrand and the Ethics Committee of the private cancer care centre will approve the study. Should you have any questions regarding the ethical aspects of the study, you can contact the chairperson of the Ethics Committee of the University of the Witwatersrand, Prof Peter Cleaton-Jones on + 27 011-7172100 or e-mail Peter.Cleaton-Jones@wits.ac.za.

Thank you for taking the time to think of joining the study. If you have any further questions, please contact me.

Yours sincerely,

Theola Potgieter (Oncology Nurse) Cell 082 327 2045

INFORMED CONSENT

I confirm that I have been informed by the investigator about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Patient Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including my personal details will be anonymously processed into a research report. I understand that I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant's name _____ (Please print)

Participant' signature _____ Date _____

Investigator's name _____ (Please print)

Investigator's signature _____ Date _____

I, …….. (field worker) herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Witness's name* _____ (Please print)

VERBAL PARTICIPANT INFORMED CONSENT (applicable when participants cannot read or write or are unable to do so for any reason as a means of ratifying the mark given by the participant instead of a signature

I, the undersigned, ……. (field worker) have read and have explained fully to the participant, named …… and/or his/her relative, the participant information leaflet, which has indicated the nature and purpose of the study in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that she understands that she will be free to withdraw from the study at any time for any reason and without jeopardizing her relationship with the health care team.

I hereby certify that the participant has agreed to participate in this study.

Participant's Name _____ (Please print)

Investigator's Name _____ (Please print)

Investigator's Signature _____ Date _____

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, ... have consented to be a participant in the study being conducted by Theola Potgieter and have been asked to give my consent to the interview being audio-taped to aid accurate collection and analysis of the information.

I give my consent for the interview being audio-taped ☐

I do not consent to the interview being audio-taped ☐

Patient's signature or mark .....

Investigator's signature .....

ADDENDUM B and B[1]

INFORMATION LEAFLET AND INFORMED CONSENT (FAMILY)

Title: The need for palliative chemotherapy. A patient, family and nurse perspective.

Dear Family Member

My name is Theola Potgieter. I have been practicing at the private ambulatory cancer care centre for 6 years. I would like to invite you to take part in a study that I am conducting at the private cancer care centre. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to phone me, Theola Potgieter at 041-363 0581during office hours (08:00 – 17:00), or after hours on 082 327 2045. You should only agree to take part if you are completely satisfied with all the procedures involved.

WHAT IS THE STUDY ALL ABOUT?

The study is about understanding why patients prefer to get palliative chemotherapy, what they expect by choosing this treatment and how they, their families and nurses experience the treatment. I would therefore also like to explore the family member's experience and expectations.

WHAT WILL YOU NEED TO DO IN THE STUDY?

If you would like to join the study, I will first ask you to sign a consent form. This form is to show that you will allow me to interview you and include the information that you give me in a scientific report. Then I would invite you to tell me a little of yourself like how old you are and where you come from. Then I will ask you to tell me about your experience of the

palliative chemotherapy your family member is receiving. The interview will take about an hour of your time.

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You have to be a family member of a patient receiving palliative chemotherapy at the private cancer care centre. You also need to be older than 18 years.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

You might become sad when you tell me about your family member's illness. Unfortunately this is the only way that I can find out how you experience the illness and treatment. If you are upset I will be able to refer you to a social worker experienced in counselling oncology patients to give you some assurance. Remember that you may decide at any time during the interview that you don't want to be in the study. You are perfectly within your rights and, if you do decide to withdraw, your decision will not have any effect on the normal treatment and care you or your family member will receive.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

By participating in this study you will help me to find out more about the experience and expectations of the family member of patients receiving palliative chemotherapy. When nurses are able to understand why patients choose palliative treatment it and what the family's experiences and expectations are, it would assist them to educate, advise and support patients receiving palliative chemotherapy as well as their families better. There are, however, no benefits for you personally and you will not be paid for your participation.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

You can choose if you want to take part in the study. You can also, during the interview, say that you do not want to take part any more. You can even tell me that I cannot use the information after you have talked to me. Once I have typed what you have said, I will erase your name and nobody will be able to identify your information. This means I cannot end your participation any more as I also would not know which information is yours and which information has been given to me by another person I have interviewed.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED FOR THE STUDY?

What you say to me is confidential and only the researcher (myself) would be able to have access to your information. I will not identify you in any way on our records – your information will be given a code number which cannot be traced back to your name. When I type what you said, I will remove your name and your name will not be used when we write the report.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Before asking you to take part in the study, the Human Research Ethics Committee (Medical) of the University of the Witwatersrand and the Ethics Committee of the private cancer care centre will approve the study. Should you have any questions regarding the ethical aspects of the study, you can contact the chairperson of the Ethics Committee of the University of the Witwatersrand, Prof Peter Cleaton-Jones on + 27 011-7172100 or e-mail Peter.Cleaton-Jones@wits.ac.za.

Thank you for taking the time to think of joining the study. If you have any further questions, please contact me.

Yours sincerely,

Theola Potgieter (Oncology Nurse) Cell 082 327 2045

INFORMED CONSENT

I confirm that I have been informed by the investigator about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Family/significant other Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including my personal details will be anonymously processed into a research report. I understand that I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant's name _____ (Please print)

Participant' signature _____ Date _____

Investigator's name _____ (Please print)

Investigator's signature _____ Date _____

I, …….. (field worker) herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Witness's name* _____ (Please print)

VERBAL PARTICIPANT INFORMED CONSENT (applicable when participants cannot read or write or are unable to do so for any reason as a means of ratifying the mark given by the participant instead of a signature

I, the undersigned, …… (field worker) have read and have explained fully to the participant, named …… and/or his/her relative, the participant information leaflet, which has indicated the nature and purpose of the study in which I have asked the participant to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that she understands that she will be free to withdraw from the study at any time for any reason and without jeopardizing her relationship with the health care team.

I hereby certify that the participant has agreed to participate in this study.

Participant's Name _____ (Please print)

Investigator's Name _____ (Please print)

Investigator's Signature _____ Date _____

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, ... have consented to be a participant in the study being conducted by Theola Potgieter and have been asked to give my consent to the interview being audio-taped to aid accurate collection and analysis of the information.

I give my consent for the interview being audio-taped ☐

I do not consent to the interview being audio-taped ☐

Family member/significant other's signature or mark .....

Investigator's signature .....

INFORMATION LEAFLET AND INFORMED CONSENT (NURSE)

Title: The need for palliative chemotherapy. A patient, family and nurse perspective.

Dear Colleague

My name is Theola Potgieter. I have been practicing at the private oncology care centre for the past 6 years. I would like to invite you to take part in a study we are conducting at the private cancer care centre. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in the study, you should fully understand what is involved. If you have any questions which are not fully explained in this leaflet, do not hesitate to phone me, Theola Potgieter at 041-363 0581during office hours (08:00 – 17:00), or after hours on 082 327 2045. You should only agree to take part if you are completely satisfied with all the procedures involved.

WHAT IS THE STUDY ALL ABOUT?

The study is about understanding why patients prefer to get palliative chemotherapy, what they expect by choosing this treatment and how they experience the treatment. The study is also about understanding the family member's experience and expectations of palliative chemotherapy. During this study I would also like to explore the nurse caring for the patient receiving palliative chemotherapy's experiences and expectations.

WHAT WILL YOU NEED TO DO IN THE STUDY?

If you would like to join the study, I will first ask you to sign a consent form. This form serves as evidence that you will allow me to interview you and include the data in a scientific report. Then I would invite you to give me some general information about yourself. I will ask you to tell me about your experience and expectations as a nurse caring for patients receiving palliative chemotherapy. The interview will take about an hour of your time.

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You have to be a registered or enrolled nurse caring for patients receiving palliative chemotherapy at this specific private cancer care centre.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

You might experience emotional discomfort during the interview. Unfortunately this is the only way that I can find out more about your experiences and expectations as a nurse caring for a patient receiving palliative chemotherapy. If you are upset I will be able to refer you to social worker experienced in counselling to support you. Remember that you may decide at any time during the interview that you want to withdraw from the study. You are perfectly within your rights and, if you do decide to withdraw, your decision will not have any effect on your employment at this cancer care setting.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

By participating in this study you will help me to find out why patients would like to be treated with palliative chemotherapy, what they expect from this treatment and what they experience when having this treatment. You will also help me to understand the nurse's experience and expectations of palliative chemotherapy. When nurses are able to understand why patients choose palliative treatment it is would assist them to educate, advise and support patients receiving palliative chemotherapy as well as their families better. Having insight into what nurses experience would also assist with developing interventions to support them. There are, however, no benefits for you personally and you will not be remunerated for participating.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

Participation is voluntary. You can also, during the interview as well as after the interview, withdraw from the study. However, once the interview has been transcribed, I will erase your name and nobody will be able to link the transcription to a specific name. This means I cannot end your participation any more.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED FOR THE STUDY?

What you say to me is confidential and only I will have access to your information. I will not identify you in any way on my records – your information will be given a code number which cannot be traced back to your name. When the interview is transcribed, I will remove your name and your name will not be used when we write the report.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Before asking you to take part in the study, the Human Research Ethics Committee (Medical) of the University of the Witwatersrand and the Ethics Committee of the private cancer care centre will approve the study. Should you have any questions regarding the ethical aspects of the study, you can contact the chairperson of the Ethics Committee of the University of the Witwatersrand, Prof Peter Cleaton-Jones on + 27 011-7172100 or e-mail Peter.Cleaton-Jones@wits.ac.za.

Thank you for taking the time to think of joining the study. If you have any further questions, please contact me.

Yours sincerely,

Theola Potgieter (Oncology Nurse) Cell 082 327 2045

INFORMED CONSENT

I confirm that I have been informed by the investigator about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information (Nurse Information Leaflet and Informed Consent) regarding the study.

I am aware that the results of the study, including my personal details will be anonymously processed into a research report. I understand that I may withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant's name _____ (Please print)

Participant' signature _____ Date _____

Investigator's name _____ (Please print)

Investigator's signature _____ Date _____

I, …….. (field worker) herewith confirm that the above participant has been informed fully about the nature, conduct and risks of the above study.

Witness's name* _____ (Please print)

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, ... have consented to be a participant in the study being conducted by Theola Potgieter and have been asked to give my consent to the interview being audio-taped to aid accurate collection and analysis of the information.

I give my consent for the interview being audio-taped ☐

I do not consent to the interview being audio-taped ☐

Nurse's signature .....

Investigator's signature .....

ADDENDUM D

TOPIC GUIDE (PATIENT)

Section A: General information

			Office use
Cultural group	.....		Q1=
Home language	English	1	Q2=
	Afrikaans	2	
	Xhosa	3	
	Other	4	
Age	.....years		Q3=
Gender	Male	1	Q4=
	Female	2	
Marital status	Married	1	Q5=
	Divorced/separated	2	
	Single	3	
	Widowed	4	
	Co-habiting	5	
Educational level	Never went to school	1	Q5=
	Up to grade 7	2	
	Grade 8 – 10	3	
	Grade 11 – 12	4	
	Tertiary	5	

Diagnosis (from patient's file)	.....		Q6=
ECOG performance status (from patient's file)	PS0	1	Q7=
	PS1	2	
	PS2	3	
	PS3	4	
	PS4	5	

Section B: Interview themes

- Reasons for undergoing palliative chemotherapy
- Expectations
- Experience
- Side-effects experienced

ADDENDUM E

TOPIC GUIDE (FAMILY)

Section A: General Information

			Office use
Cultural group	……		Q1=
Home language	English	1	Q2=
	Afrikaans	2	
	Xhosa	3	
	Other	4	
Age	…….years		Q2=
Gender	Male	1	Q3=
	Female	2	
Educational level	Never went to school	1	Q4=
	Up to grade 7	2	
	Grade 8 – 10	3	
	Grade 11 – 12	4	
	Tertiary	5	

Relationship to patient	……		Q5=

Section B: Interview themes

- Feelings about the patient's decision to undergo palliative chemotherapy
- Expectations
- Experience
- Side effects observed

ADDENDUM F

TOPIC GUIDE (NURSE)

Section A: General information

			Office use
Cultural group	……..		Q1=
Home language	English	1	Q2=
	Afrikaans	2	
	Xhosa	3	
	Other	4	
Age	……..years		Q3=
Gender	Male	1	Q4=
	Female	2	
Educational level	Basic nursing training	1	Q5=
	Oncology trained	2	

Years experience in the field	……..years		Q6=
of oncology nursing			

Section B: Interview themes

- Feelings about palliative chemotherapy
- Expectations
- Experiences

ADDENDUM G

DATA ANALYSIS PROTOCOL

The following steps will be followed when transcribing the data:

1. Get a sense of the whole. Read through all of the transcriptions carefully. Jot down some ideas as they come to mind.
2. Take one document (one interview). Go through it ask yourself, what is this about? Do not think about the "respondent" of the information, but rather the underlying meaning. Write thoughts in the margin.
3. When you have completed this task for several informants, make a list of all topics. Cluster together similar topics. Form these topics into columns that might be arrayed as major topics, unique topics, and leftover.
4. Now take the list and go back to your data. Abbreviate the topics as codes next to the appropriate segments of the text. Try out this preliminary organizing scheme to see whether new categories and codes emerge.
5. Find the most descriptive wording for your topics and turn them into categories by grouping topics that relate to each other. Perhaps draw lines between your categories to show interrelationships.
6. Make a final decision on the abbreviation for each category and alphabetize these codes.
7. Assemble the data material belonging to each category in one place and perform a preliminary analysis.
8. If necessary, recode your existing data.

ADDENDUM H

APPROVAL LETTER FROM ETHICS COMMITTEE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Theola Potgieter

CLEARANCE CERTIFICATE	**M120601**
PROJECT	The Need for Palliative Chemotherapy: A Patient, Significant Other and Nurse Perspective
INVESTIGATORS	Mrs Theola Potgieter .
DEPARTMENT	Department of Nursing Education
DATE CONSIDERED	29/06/2012
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 27/08/2012 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Prof Lize Maree

DECLARATION OF INVESTIGATOR(S)
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

ADDENDUM I

APPROVAL LETTER FROM GVI

gvi oncology

Dr L Gouws & Partners Inc.

info@cancercare.co.za . www.cancercare.co.za

To whom it may Concern

Date :1/ 07/ 2012

GVI Oncology Research committee herby gives permission to:

Theola Potgieter to conduct research

At the LDOC oncology unit in Port Elisabeth

Topic: **THE NEED FOR PALLIATIVE CHEMOTHERAPY. A PATIENT, FAMILY AND NURSE PERSPECTIVE.**

We acknowledge the ethical approval provided by Wits school of nursing

The only requirement will be that the GVI research committee gets a copy of final research report to study the results and recommendations of the research project

Yours sincerely

Linda Greeff

For the GVI Research committee