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THE TRANSITION FROM PALLIATION WITH ANTI-CANCER TREATMENT TO PALLIATION WITHOUT ANTI-CANCER TREATMENT: A PATIENT AND FAMILY EXPERIENCE

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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

March 2015

DECLARATION

I declare that the study on **THE TRANSITION FROM PALLIATION WITH ANTI-CANCER TREATMENT TO PALLIATION WITHOUT ANTI-CANCER TREATMENT: A PATIENT AND FAMILY EXPERIENCE** 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

To my beautiful daughters Hielét and Jomari.

I hope I can inspire you to be the best you can be and to my mother, that still inspires me every day.

ACKNOWLEDGEMENTS

I would like to recognise the following people who supported me during this study and helped making it possible:

- My husband Pieter, my daughters Hielét and Jomari for their love, support and loads of patience.
- My Mother, “Oom Willem”, Riaan and Liza for their constant motivation and for believing in me.
- To my friends and colleagues at Outeniqua Oncology for cheering me on from the sideline.
- To Prof Maree for her supervision, patience and positive influence and always having some encouraging words.
- To all the participants who shared their experiences with me even though it had to be very difficult.
- To GVI Oncology for giving me this great opportunity.

ABSTRACT

Cancer is a growing public health problem and killed slightly more than 8 million people in 2012 of which 5.3 million lived in the less developed regions of the world. Anti-cancer therapies such as radiotherapy, chemotherapy and surgery can be used to palliate cancer patients. The decision to stop anti-cancer treatment is a sensitive and difficult one and agreement between patient and physician and timing are important factors to consider when making such a decision. When transitioning from receiving palliative anti-cancer treatment to palliative care without anti-cancer treatment, patients are referred to other health care professionals for “pure” palliative care. As a result, the patient and family have to leave behind the care they received from the health care professionals involved in the anti-cancer treatment – a situation which could add to their suffering. The purpose of the study was to explore how patients treated at a private cancer care setting in the Southern Cape region of South Africa and their families experienced the transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment.

An exploratory qualitative design was selected for this study. The study setting was an oncology unit in the Southern Cape forming part of the private health care sector. The population consisted of all patients and their families treated at the specific oncology unit who were transitioning from palliation with anti-cancer treatment to palliation without anti-cancer treatment. Purposive sampling selected the sample, whilst qualitative interviews were used to gather the data. The data were analysed using Tesch’s open coding approach. The theory of Navigating Unknown Waters underpinned the study.

Eighteen (18) people participated in the study - nine patients and nine family members. Four themes arose from the data gathered from the patient participants and three themes arose from the family member’s data.

Transitioning from palliation with anti-cancer treatment to palliation without anti-cancer treatment was a traumatic experience for both the patients and their families, which added to their suffering. When learning nothing more could be done, patients and family participants experienced shock. Being confronted with death made patient participants feel scared and for some, euthanasia seemed to be an option whilst others hoped for a cure with alternative therapies. Some family members were able to accept the impending death of the patient, whilst others did not want to think of what was lying ahead. Both the family and the patient`s felt sad and some, even abandoned by the health care team responsible for the palliative chemotherapy, whilst others were happy to be referred to a palliative care team. Participants had to deal with a large symptom burden, with pain

being the most debilitating of all. Family participants felt distressed and helpless whilst having to care for the terminally ill patient, during which time having to witness the deterioration of their loved one.

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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Little is known about what patients and their families experience during the transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment, as only a few studies conducted in developed countries such as Japan, Australia, Canada and the United Kingdom could be found. In addition, Maree and Schmollgruber (2014) identified a lack of South African nursing research focusing on the patient living with cancer and the family. It might be argued that international studies can inform nurses practicing in cancer care settings about this phenomenon, but South African cancer patients might experience different challenges due to the difference in the health care systems, access to health care and life style. This study would provide base line data and allow the identification of similarities and differences in terms of the topic under study and attempts to address the identified knowledge gap.

1.2 BACKGROUND

Cancer is a growing public health problem and according to the latest GLOBOCAN statistics (International Agency for Research on Cancer and World Health Organization 2014), there were more than 14 million people newly diagnosed with cancer in 2012 of which more than 8 million lived in the less developed regions of the world. In the same year, cancer killed slightly more than 8 million people of which 5.3 million lived in these less developed regions.

Nearly 50% of all new cancer patients will die within 12 months of diagnosis as the five year survival rates for all cancers in developing and developed countries range from 30 to 60% (Kaur & Mohanti, 2011). Cancer exacts a toll of suffering well beyond that which can be easily measured. According to the Expert Committee of Cancer Pain Relief and Active Support of the World Health Organization (WHO) (Weinstein, 2001), pain and symptom control should be high priority in cancer care.

The palliative concept of care is the best method to manage the majority of terminally ill oncology patients. Palliative care is appropriate when cure is no longer possible and allows the patient to live the remainder of life as free from pain and other symptoms as possible. Palliative care offers comfort for not only the patient, but also the members of the family so that when death comes, it can be painless, peaceful and dignified (Schonwetter, 1996).

Anti-cancer therapies such as radiotherapy, chemotherapy and surgery can be used to palliate cancer patients (Green & Youll, 2007). According to Hoskin, as cited by Green and Youll (2007), palliative treatment should be given when cure is no longer possible with the intent of symptom control and by only using treatment which would interfere minimally with the patient's lifestyle. The decision to stop anti-cancer treatment is a sensitive and difficult one and agreement between patient and physician and timing are important factors to consider when making such a decision (Kaur & Mohanti, 2011). This transition results in the loss of life as it was previously known. This loss needs to be grieved with the resulting anger, anxiety and sadness to allow the patient and family to adapt to this changed life (Evans, Tulsky, Back & Arnold, 2006).

1.3 RESEARCH PROBLEM

When transitioning from receiving palliative anti-cancer treatment to palliative care without anti-cancer treatment, patients, in the cancer care setting where the researcher practices as oncology nurse, are referred to other health care professionals for "pure" palliative care. As a result, the patient and family have to leave behind the care they received from the health care professionals involved in the anti-cancer treatment – a situation which could add to their suffering. It is not clear how patients receiving palliative anti-cancer treatment in South Africa and their families experience the transition to palliative care without anti-cancer treatment as this seems to be an under researched topic. The research question for the study was therefore: *How do patients treated at a private cancer care setting in the Southern Cape region of South Africa and their families experience the transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment?*

1.4 PURPOSE OF THE STUDY

The purpose of the study was to explore how patients treated at a private cancer care setting in the Southern Cape region of South Africa and their families experienced the transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment.

1.5 THEORETICAL FRAMEWORK OF THE STUDY

The theoretical foundation selected for the study is the upcoming transitional theory of Navigating Unknown Waters. The theory of Navigating Unknown Waters provides a better understanding of the transitions experienced by palliative care patients suffering from advanced cancer and their families, as well as the psychological processes involved in adapting to these transitions (Duggleby, Penz, Goodridge, Leipert, Berry & Justice, 2010). This theory was selected as the researcher is in agreement with most of the transitional processes illustrated in this theory.

1.6 THE STUDY

An exploratory qualitative design (Grove, Burns & Gray, 2013) was selected for this study. The study setting was an oncology unit in the Southern Cape forming part of the private health care sector. The population consisted of all patients and their families treated at the specific oncology unit who were transitioning from palliation with anti-cancer treatment to palliation without anti-cancer treatment and their families. Purposive sampling (Burns and Grove, 2009) selected the sample, whilst qualitative interviews were used to gather the data (McCance and Mcilfatrick 2008). The data were analysed using Tesch's open coding approach as described by Creswell (1994). The principles outlined by Shenton (2004) were used to enhance the trustworthiness of the study.

1.7 CONCEPT CLARIFICATION

Family = For the purpose of the study family was defined as the significant other/s identified by the patient.

Transition = The word "transition" means the process or a period of changing from one state or condition to another (Oxford English Dictionary, 1989).

Anti Cancer Treatment = Any drug or intervention used in the prevention or treatment of cancer.

1.8 OUTLINE OF THE 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 the study was introduced to the reader. In Chapter 2 an overview of the literature applicable to the study will be presented.

2.2 CANCER AS WORLD WIDE HEALTH PROBLEM

Cancer is a worldwide health problem affecting more people each year. The most recent GLOBOCAN statistics (International Agency for Research on Cancer and World Health Organization, 2014) indicates there were more than 14 million people newly diagnosed with cancer in 2012, of which more than 8 million lives in the less developed regions of the world. In the same year, cancer killed slightly more than 8 million people, of which 5.3 million lived in these less developed regions. As evident from these statistics, cancer places its heaviest burden on the poor and the disadvantaged populations, probably due to demographic growth, changing lifestyles, unhealthy habits and the lack of control of cancer associated diseases (Aulukh, 2011). Aulukh (2011) concurs with the GOLBOCAN statistics and states that more than half of cancer deaths each year occur in the developing countries and warns that if action is not taken to tackle the growing, global public-health problem, an estimated 5.9 million and 9.1 million cancer deaths might occur in 2015 and 2030 respectively. By current global estimates, nearly 7 million of the 11 million newly diagnosed cancer patients present in advanced stages and approximately 50% of all new cancer patients will die within 12 months of diagnosis, as the five year survival rates for all cancers in both developing and developed countries range from 30 to 60% (Kaur & Mohanti, 2011).

Cancer exacts a toll of suffering that cannot be measured. According to the Expert Committee of Cancer Pain Relief and Active Support of the World Health Organization (Weinstein, 2001), pain and symptom control should be highest priority in cancer care.

According to Danaei, Vanderhoorn, Lopez, Murray and Ezzati (2005) one in every three cancer deaths, from the 7 million deaths that occurred, was caused by nine risk factors. From these nine factors, two of these, namely smoking and alcohol, played an important role in both high-income as well as low and middle-income countries. Although it was

found some cancers, i.e. prostate, kidney, melanoma and lymphomas, were not linked to any of the risk factors, other cancers such as cervical cancers could directly be linked to risk factors like the sexual transmission of the Human Papilloma Virus causing cervical cancer. It was also found that in low and middle income countries such as Central Asia smoking, alcohol use and low fruit and vegetable intake and the sexual transmission of the human papilloma virus were the most important risk factors. In high income countries, smoking, alcohol use, overweight and obesity were the most important attributing factors to cancer deaths (Danaei et al., 2005).

According to the WHO (2014) 30% of cancer deaths are due to five leading behavioural and dietary risks namely:

- High body mass index
- Low fruit and vegetable intake
- Lack of physical activity
- Tobacco
- Alcohol use.

In addition, tobacco is the most important of all these factors, causing 20% of global cancer deaths and attributing to 70% of lung cancer deaths in low and middle income countries, viral infections such as human papilloma virus are responsible for 20% of cancer deaths (WHO, 2014). The WHO (2014) states lung, liver, stomach, colorectal and breast cancer are the most prevalent cancers in the world with 60% of people newly diagnosed with cancer coming from Africa, Asia and Central and South America.

According to Sitas, Parkin, Chirenje, Stein, Mqoqi and Wabinga (2006), cancer registration in underdeveloped countries, such as countries in the Sub-Saharan Africa region, is problematic. This is due to the fact that cancer patients can only be registered when they end up at health care services, as many of the rural areas don't have health care services available. In urban areas where health care services are available some only seek medical attention when their disease is in an advanced stage. The top six cancers in Sub Saharan Africa are listed in Table 2.1.

Table 2.1: The top six cancers in men and women living in sub-Saharan Africa

Top Six Male Cancers	**Top six Female Cancers**
Kaposi`s Sarcoma	Cervix
Liver	Breast
Prostate	Kaposi`s Sarcoma
Esophagus	Liver
Non-Hodgkin`s Lymphoma	Stomach
Stomach	Non-Hodgkins Lymphoma

(Source: Sitas et al., 2006).

In South Africa, the cancer registry was established in 1986 and is under the management of the National Health Laboratory Service-National Institute for Occupational Health (NIOH). Unfortunately the statistics have challenges in terms of updating the registry but according to the 2007 statistics, prostate and breast cancer were the most common cancers in men and women. The top five cancers in men and women are presented in Table 2.2.

Table 2.2: The top five cancers in men and women according to the South African Cancer Registry, 2007.

Top 5 Male Cancers	**Top 5 Female cancers**
Prostate	Breast
Cancer of an unknown origin	Cervical
Lung	Cancer of an unknown origin
Kaposi Sarcoma	Kaposi Sarcoma
Colorectal	Colorectal

(Source: NIOH, 2007)

2.3 CANCER TREATMENT

Schonwetter (1996) divides cancer patients into four categories based on the therapy they receive: traditional/curative, palliative (active), palliative (symptomatic) and supportive. Cancer treatment consists of various modalities and includes surgery, radiotherapy and chemotherapy (Lester, 2007). Surgery and radiotherapy are localised treatments whilst chemotherapy is a systemic treatment (Otto, 2007). In cancer care, surgery is used for the diagnosis and staging of cancer, treatment, rehabilitation and reconstruction and palliation (Lester, 2007).

Radiotherapy in oncology is defined as the use of ionising radiation in the treatment of malignant diseases and focuses on delivering the exact dose of radiation to a defined tumour volume whilst restricting damage to healthy tissue optimally. Radiotherapy can be used as a single treatment modality or in conjunction with surgery, chemotherapy, biotherapy, heat or oxygen (Aistars, 2007).

Chemotherapy is the use of cytotoxic drugs in the treatment of cancer (Otto, 2007) and is used in six different ways:

- Adjuvant therapy- chemotherapy in conjunction with other treatment such as surgery or radiation.
- Neoadjuvant chemotherapy- chemotherapy used to shrink a tumour before surgery.
- Primary therapy- used in treatment of patients with localised disease for which alternative treatment is available, but is less effective.
- Induction therapy- cytotoxic drugs as primary treatment, where no other alternative is available.
- Combination chemotherapy- treatment with two or more chemotherapeutic agents to treat cancer where the one medication enhances the action of the other (Otto, 2007).

2.3.1 Palliative treatment

As illustrated above, anti-cancer therapies such as radiotherapy, chemotherapy and surgery can also be used to palliate the patient`s symptoms (Green & Youll, 2007). According to Hoskin as cited by Green and Youll (2007), palliative treatment should be given when cure is no longer possible. Palliative treatment focuses on symptom control using treatment that would cause the minimum disturbance to the patient’s lifestyle. According to Jeffrey (1995), the aim of anti-cancer treatment in palliation is to maximise the quality of life of the patient by promoting his capacities to make and take responsibility for his own choices. Unfortunately palliative treatment is not often viewed as a separate

entity to disease orientated treatment and care as patients are still considered to be undergoing “active” treatment.

The decision to forego anti-cancer treatment is a sensitive and difficult situation and the decision to stop anti-cancer treatment should be made by the patient, family and the oncologist. Agreement and timing are important factors to consider when making such a decision (Kaur & Mohanti, 2011) as this causes great distress to cancer patients and their families. As the oncologist is responsible for the medical management of the cancer patient, the oncologist should ensure the patients have an ongoing holistic care plan when anti-cancer therapies are stopped and they approach the end of life (Cherny, 2010).

According to Cherny (2010), oncologists should be familiar with methods used to measure pain and other physical and psychological symptoms such as dyspnoea, fatigue, nausea and vomiting, depression and anxiety and desire for euthanasia. This, however seems to be a challenge as Cherny (2010), in a study exploring ESMO members’ involvement in palliative care, found that 42% of respondents reported they had not received sufficient training in palliative care during their training as medical practitioners. This finding is consistent with published data regarding the need for training of medical oncologists in the field of pain management, communication and palliative care (Cherny, 2010: 413).

Lack of palliative care knowledge and competency is not limited to oncologists. Bradley (2001) found that nurses are not knowledgeable about palliative care. Nearly two-thirds of the nurses who participated in the study had some palliative care training but less than 30% felt they knew enough to have a conversation with the patients and their families. In addition, the nurses did not feel comfortable to inform patients and families on when it was time to stop anti-cancer treatment and to start palliative care.

Even though palliative chemotherapy is only administered for symptom control, patients still experience side effects, therefore palliative patients need to compare the benefits against the side effects they might experience. It was positive to find that Griffin, Butow, Coates, Childs, Ellis, Dunn and Tattersall (1996) discovered that treatment decisions were not only made by the health care practitioners, but patients were also included in choices of having therapy or not. This means that patients need to be informed of all the issues concerning their disease and treatment.

Patients reported experiencing various physical symptoms after receiving palliative chemotherapy including alopecia, nausea, fatigue, vomiting, increased urination, dry skin, loss of appetite, difficulty sleeping, taste changes and oral mucositis. In addition, the most reported psychosocial problems included the thought of coming for treatment, depression,

the effect on the family or partner, feeling anxious, the effect on their work, effect on social activities, the thought of having a needle, the length of time treatment took, the loss of sexual feeling and forgetfulness. It is clear the side effects caused by palliative chemotherapy have a considerable influence on the quality of life of the cancer patient and the family, as the family supports the patient while going through the side effects when they occur at home (Griffin et al., 1996). Griffin et al. (1996) advised that the benefits of having treatment versus the side effects should be continuously assessed and to reach the point where the dose administered is effective in managing the cancer but with the lowest toxicity for the patient.

Even though chemotherapy in the palliative care setting should only be administered for symptom control, Wright, Zhang, Kheating, Weeks and Prigerson (2014) in a study conducted in the USA found between 20% and 50% of patients with incurable cancer receive chemotherapy within thirty days of their death. In addition, having chemotherapy within the last four months before death is associated with a higher risk of ending up in an Intensive Care Unit, being mechanically ventilated or receiving cardiopulmonary resuscitation in the patient`s last week of life. Receiving chemotherapy at end-of-life causes patients being referred late to the hospice care team and they are not likely to die at their preferred place as planned. All of these factors contribute to a worse quality of life for the patient, higher stress for the caretaker or family and higher medical costs (Wright et al., 2014).

2.4 THE CANCER EXPERIENCE

The diagnosis of cancer is extremely shocking to the patient, not only for the immediate effect it`s going to have on the patient`s life, but also for the loss of life as he or she knows it and with an unsure future (Wells, 2008). According to Wells (2008), the emotional impact cancer has on the patient is influenced by the experiences leading up to the learning of the diagnosis of cancer, the individual`s perception of cancer and its meaning, the disruption the disease and treatment causes to normal life, perceptions surrounding treatments and its effects, individual personality and coping styles. In addition, cancer affects all patients in a different way and the health care practitioner cannot predict what effect all the treatments of choice for the specific disease will have on the patient.

For most cancer patients and their families their religion is an important factor in how they experience their cancer and most patients need help with their spiritual needs. In addition, cancer changes the patient’s definition of himself as he is not able to fulfil his previous role

as a working individual, a spouse or parent. Cancer is most threatening to the patient when it takes away the patient`s hope (Peteet & Balboni, 2013).

2.4.1 Transitions in care

According to Kralik, Visentin and Van Loon (2005) transition is an important concept because the word can only be defined in the disciplinary focus it is used. It involves people`s experiences during a passage of change. Bridges (Reimer, Davies & Martens, 1991) defines transition as something which starts with a specific period ending and followed by a period of confusion and distress which leads to new beginnings. According to Larkin, Djerckx De Casterle and Schotsmans (2007), Freud described transition as "an emotional state where the quality of the present moment may be all the more meaningful because of its fragility and impermanence" (p20).

Parkes (Reimer et al., 1991) proposed psychological transition, which he defines as a change that obligates the individual to change his current assumptions and develop new ones to help this individual to cope or adapt with his new situation. Transition is mostly brought on by stressful life events and the changes brought on by this are described as the beginning of the transition.

According to Ronaldson and Devery (2001) transition is one of the most confusing and confronting times for patients and health care professionals. Duggleby et al. (2010), in a study conducted in Canada, found that patients and families facing end of life are faced with multiple transitions which occur in the environment, physical and mental health, roles and relationships and activities of daily living.

The transition from a curative care service to palliative care is an uncertain time for the patient and the care giver and can cause a lot of sorrow and suffering which could be lessened by being informed and knowledgeable about palliative care (Ronalson & Devery, 2001). According to Davies (Ronaldson & Devery, 2001: 172), transition must be seen to be more than just being referred from a health care service to a palliative care service and should be seen as the "individual`s passage through one set of hopes and expectations to another"(p172). Nurses play a pivotal role in this transition as they have a great influence on the continuity of palliative care and on the patient. If nurses have a good understanding of palliative care and they inform the patient and family adequately, the transition will be less uncertain (Ronaldson and Devery, 2001).

2.4 CARING FOR THE PATIENT AND FAMILY

2.5.1 Supportive versus palliative care

There are two philosophies of care to cancer patients; supportive care and palliative care. It seems as if there is confusion about the difference between supportive care and palliative care and it is unclear where the one stops and the other starts. The European Society of Medical Oncology (ESMO) (Cherny, 2010) has developed two definitions which separate the two types of care. According to these definitions, supportive care is involved in the comfort and social support of the family and the patient at all the stages of the patient`s illness; palliative care is care which aims to establish comfort and social support of the patient and his family when cure is not possible. Although these two stages overlap, it is when the illness reaches a stage of incurability with all the implications for the patient and family that palliative care sets in. Supportive care is needed by every patient continuously, where palliative care only specialises on the needs of patients who are incurable. Ultimately the distinction between supportive care and palliative care is mainly concerned with the stage of the illness of the patient.

Fadul, Elsayem, Palmer, Fabbro, Swint, Li, Paulter and Bruera (2009) in a study conducted at the University of Texas, Houston, found that patients and health care professionals prefer the term supportive care rather than palliative care. The authors found using the term “palliative care” was a barrier to timely referral, because patients and families associate the term with end-of-life care and giving up hope. In addition, the name “supportive care” was less distressing for patients and health care practitioners. However it might cause the practitioner to never have the end-of-life discussion with the patient and these patients end up being unprepared for what to expect during the terminal phase of their disease.

Fadul et al. (2009) also found the majority of their participants (61%) in their study associated “supportive care” as a support programme for side effects of active anti-cancer therapy such as chemotherapy. Clinical participants involved in the study agreed there is a place for palliative services and although they are willing to refer, it still occurs that these palliative patients are only referred when they are end-of-life. Clinical participants associated palliative care with hospice care, were uncomfortable with having the end-of-life discussions and were worried this might take away hope from the patient and their family. Clinicians were also more lenient towards the use of the word supportive care when discussing referral to such a care centre.

However, Milne, Jefford, Schofield and Aranda (2013) do not agree that changing the name from “palliative care” to “supportive care” will help with timely referral and may only lead to confusion. Communication is the key to timely referral and by seeking understanding of what palliative care means to the caregiver and patient some of the confusion can be cleared. According to Schonwetter (1996), the palliative concept of care is the best method to manage the majority of terminally ill oncology patients, as palliative care is appropriate when cure is no longer possible and allows the patient to live the remainder of life as free from pain and other symptoms as possible. It offers comfort for not only the patient, but also the members of the family so that when death comes, it can be painless, peaceful and dignified.

The researcher is of the opinion that even if the term palliative care is changed to supportive care it would not prevent patients from only seeking help when they enter the end-of-life phase. The researcher experienced that patients’ say they don’t think about dying and that they will take it day by day and will address the problems as they arise. It seems as if patients feel they are giving up hope if they consent to be referred to a Hospice care centre. In addition, it seems as if families sometimes manipulate the patients to continue with anti-cancer treatment, even though they can see that the patient is not gaining from it, because they are too scared to “Navigate Unknown Waters”. This affects the patient`s quality of life during this end-of-life stage.

2.5.2 Palliative care

The World Health Organization (2014) defines palliative care as “an approach that improves the quality of 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, psychosocial and spiritual.” Schonwetter (1996) is however of the opinion that palliative care is an exercise in forward planning and prevention rather than a model of crisis intervention and suggests palliative care should be included as the fourth phase of a comprehensive cancer prevention programme to ensure comprehensive care for all cancer patients.

Gwyther and Cohen (2009) see palliative care as a type of care that is focused on taking care of the suffering of patients and their family members. This suffering is that of the patient and family members when they are faced with the diagnosis of a life threatening illness. Suffering is a reality as Johnson, Kassner, Houser and Kutner (2005) found even

in hospice and palliative care settings, where interdisciplinary teams target the relief of symptom distress as a high priority, patients still have a significant symptom burden. It is not known if the patients still suffer this high symptom burden because their interventions were ineffective or they did not use adequate treatment (Johnson et al., 2005).

Timely referral for palliative care is of the utmost importance. Ronaldson and Devery (2001) found the lack of timely referral to palliative facilities causes the patient a great deal of shock and anxiety. Patients need time to think about what they are going through and need to discuss their situation. Patients who were not involved in the planning for palliative care, might not have any knowledge about palliative care and could have misconceptions on what is going to happen to them. Awareness of the patient`s needs will lead to timely referral to palliative care facilities.

Palliative care includes end of life care – the phase when death is imminent and acknowledges that the intensity of physical, psychological, existential, spiritual and family issues may be magnified by the patient's approaching death (Cherny, 2010:411). Palliative care also includes terminal care – the care the patient would need just before he or she passes away. Terminal care is care that focuses on symptom management and preserving the dignity of the dying patient. The first step in terminal care is to recognise dying and understanding that death is imminent and unavoidable and no efforts to prolong life are indicated. In addition, terminal care is focused on keeping the patient comfortable which contributes to the patient`s comfort and dignity. The transition to terminal care should be done gradually so the patient and his family can adapt, as for family and friends this will be the last memory of the dying person and their experience will influence their grief and bereavement (Department of Health and Science Tasmania University, 2009).

According to Peteet & Balboni (2013), terminally ill patients viewed being free from pain and being at peace with God as the most important factors influencing their quality of life at that moment. McClain, Rosenfeld and Breitbart (2003) found a significant correlation between spirituality and three factors at end of life, namely a hastened death, hopelessness and suicidal ideation. Spirituality also influences depression as it was found that depression symptoms are under control in the presence of spiritual beliefs. In contrast, if the patient was not doing well spiritually, they experienced end of life despair. In addition, spiritual wellbeing reversed the effect that depression has on hopelessness or suicidal ideation (McClain, Rosenfeld & Breitbart, 2003). According to Peteet and Balboni (2013), religious coping was associated with psychological well-being and a better quality

of life in patients with advanced cancers. All these factors help the patient and family foster hope throughout this end of life phase.

Hope is an important aspect in human existence linked to the idea of a positive future, meaning of life and spirituality. Hope can play an important role during difficult times. In palliative patients hopelessness may contribute to wishes for a hastened death (Kylma, Duggleby, Cooper and Molander, (2009). In addition, there is a fine line between truth telling and nurturing hope and it is very important to tell the truth about the patient`s diagnosis and to not enforce the patient`s unrealistic goals and hopes (Clayton, Butow, Arnold and Tattersal, 2005).

According to Clayton et al. (2005) there are six different kinds of hope in the hope spectrum in palliative care. The kinds of hope are hope for a miracle cure or spontaneous disease remission, to live longer than expected, to find worth or meaning in life, for the healing of relationships and special times with friends and family, finding spiritual meaning and finally the hope of a peaceful death.

According to Clayton et al. (2005), there are various ways to foster hope during the end of life phase. Firstly when learning the disease has reached a terminal phase the patient should immediately learn what can be done. It should be emphasised that pain and other symptoms can be controlled and it will still be possible to control these symptoms at time of death. The patient should be ensured that he will not be abandoned by the health care practitioner and that their dignity is of utmost importance. The patient and the family should be reassured they are welcome to come back to the health care practitioner for advice and equipment and that if needed, the patient can be admitted to a palliative care setting. Setting goals which no longer involve cure also fosters hope.

2.5.3 Palliative care and the family

As already mentioned, the World Health Organisation (2014) include the family in their definition of palliative care by stating that palliative care offers a support system to help the family cope during the patient's illness and in their own bereavement. Tan, Wilson, Oliver and Barton (2011) support the inclusion of the family, based on the increasing evidence that working with the whole family rather than focusing only on the patient has better outcomes for both patient and family members, which includes the caregivers.

It is evident that the family of a terminal cancer patient needs support in a holistic way, because a family is not a single entity but consists of a collection of interdependent individuals each with their own unique hopes, dreams and fears related by blood and defined by the law (Tan et al., 2011). According to Moos (1995) families are systems with individuals who are dependent on each other, but living under the same rule structure. A family can also be less formally defined by culture or a person. Families are complex and as illness is a family affair, illness of a family member threatens the family's integrity (Maher & Hemming, 2005; Wright & Leahey, 2012) as the illness or death of one member alters the balance of the system, which impacts on all other parts of it and requires the negotiation of a new balance (Tan et al., 2011). Mehta, Cohen and Chan (2009) explain when an individual in a family is threatened by a life threatening illness or death the family needs to deal with being caregivers to the dying, forcing the family to reorganise. It is not possible to remove the patient from the context of the family and interventions should not only be applicable to the patient, but also to the family caregiver and the rest of the family, as it can keep them in balance and they will have a feeling of control.

It is evident families are important because they are the framework in which the patient adjusts to in response to his disease. It is not only the patient but also the family members who experience the toll of cancer (Lewis, 1990). Northouse (2005) agrees families are deeply affected when one of their members becomes ill. By perusal of literature on families` experience of cancer, Lewis (1990) explains there is a difference between the experience of an adult family member or spouse and the experience of a child. What was interesting is the spouse did not only have to cope with their own emotional distress, but also the distress of the diagnosed partner. As cited by Lewis (1990), Gotay found the fear of disease recurrence or progression was one of the most reported problems for the patients and their partners. According to a study done by Northouse (2005), some family members reported persistent worry even when treatment was finished and that their biggest fear was the disease would recur. Family members are confused when the patient does not return to their normal life after treatment.

According to Lewis (1990: 752), families, especially families with children, have two responsibilities when dealing with cancer. These responsibilities are to maintain an environment that is beneficial for child development and to adapt to the cancer diagnosis, the treatment and whatever may follow after the diagnosis. There is not a lot of literature available on the reaction of children on a parent`s cancer. Most studies conducted, were on children of parents with chronic illnesses or depression. These diseases caused the children to feel they don't have an emotional or physical available parent (Lewis, 1990). In

these marriages there were often more marital conflict due to the disease which made the children sometimes act out. In this study by Lewis (1990), the impact of breast cancer of a mother was tested on three different age groups of children. The young school aged children (7-10) had fears of what will happen next and about the stability of the family as a unit; they felt sad, scared, worried and sometimes angry. The older school aged children (10-13) appeared pre-occupied with what was going on in their own lives, they commented on how much influence the disease had on their lives and felt they had to help more around the house and were more inquisitive about the prognosis and treatment of the disease. Interestingly adolescent children were in a phase where they needed to develop their own independence and develop their own responsible relationships, but where the mother now had cancer, this process was reversed and the adolescent child drew back to his family and was interdependent again.

As it is clear the family as a unit are affected with the diagnosis of cancer, the family should be supported as a unit. Lewis (1990) identified nine areas of family-focused support: informational support, interpretation of course of illness and anticipatory guidance, interpretation of the patient`s emotions, interpretation of illness of the school aged children, the cognitive processing of meaning of illness for family members, access to services for physical care, referral services for exceptionally distressed families and problem-focused services.

Informational support refers to disease and treatment related information needed by the family and the patient to manage the disease at their best. The information needed to answer concerns about the diagnosis, treatment and rehabilitation. The family needs verbal as well as written information to refer to when at home. The family should be given the opportunity to ask questions during any time of the treatment or disease, as at the time of diagnosis the patient and family are in a state of shock and often forget what they are told. *Interpretation of course of illness and anticipatory guidance* is the need to understand the diagnosis and every step that will happen from there on. This is a time of uncertainty for both the patient and the family. It is important to explain expected disease and treatment related symptoms to the family and the patient to prevent misinterpretation that these problems are signs of failure of treatment or even worse. This type of support is focused on future events and not current ones. *Interpretation of the patient`s emotions* is when the family does not know how to understand the patient`s emotions and are therefore negatively influenced by it. The family might be impatient with the patient as they want him to be like he was before he was diagnosed. The family also feels distressed because they don’t have the ability to deal with the patient`s emotions because of the

diagnosis. *Interpretation of illness of the school aged children* is the way the family interacts with their children. The patient and the spouse might be worried about how to tell the children about the diagnosis without frightening them too much. Individual counselling sessions with the children are advised and during these sessions the patient and spouse might also be able to decrease their anxiety. *The cognitive processing of meaning of illness for family members* refers to the fact that each individual in the family is affected by the diagnosis. Partners might be unable to vent their frustration and support groups, led by a professional counsellor, can be used for each family member to express their frustration and fears. In addition, the family needs *access to services for physical care* of the patient. When the patient is weakened by treatment or disease it is physically straining for the family to take care of the patient. The family should have knowledge of available short term referral services that is home based and can assist the family in the physical care of the patient and to seek guidance from them in how to care for the patient. *Skill-based classes* can be taken to help the patient and family learn the skills to adjust to this stage in their lives. Spouses can also learn to support the patient without distressing themselves too much. Skills to interpret the patient`s moods and emotional vulnerability can be beneficial to the partner. *Problem-focused service* is support needed to address daily problems that arise after the diagnosis of the patients. Problems like a child acting out or conflict among family members can be addressed by this service. Lewis (1990) suggested these problems can be addressed telephonically because the facilitator does not need a background of the family and can only address the current problematic situation with the nurse or the physician talking to the mother, father or child to try to resolve the situation. *Referral services for exceptionally distressed families* may be needed for some families that are highly distressed and at a breakpoint. Screening methods should be in place to identify these family members or the family as a whole and they should be referred to psychiatric services.

Northouse (2005) agrees there are factors which put families in a higher risk group than others if they occur. The first of these factors are higher symptom distress. If the family does not have practical guidelines to cope with symptoms such as pain, fatigue and sleep disorders they will not cope. Families with a higher feeling of uncertainty are also a high risk group, if they are not informed on what will happen next they will be highly distressed. They need to have access to information or to be assured that feeling uncertain during this time is normal. Multiple demands can also interfere with the family member`s adjustment to the disease. If they have a very demanding job it may be difficult for them to adjust to the demand the disease has on them, sometimes it may help to negotiate a lighter work duty for the time the family member is acting as the caretaker. The last factor

is age. A young patient with a young family and younger children is obviously in higher distress emotionally, but the older patients are burdened more with co-morbidities for the family which makes caregiving a lot more difficult.

In addition, Northouse (2005) identified several protective factors that can be beneficial to the patient and family members. These are, to get a support system in place of family members, friends, neighbours and members of their church who can relieve the family from their caregiving duties. The use of active coping strategies such as exercising or talking about problems as they occur can help the family cope with their stress. To practice positive thinking and surrounding themselves with positive people and to have goals that are achievable for the family and patient can make the whole experience less negative. The last protective factor is to find meaning in their illness and to look for things they find positive.

2.6 THEORETICAL FOUNDATION OF THE STUDY

The theoretical foundation selected for the study was the upcoming theory of “Navigating Unknown Waters” developed by Duggleby et al. (2010). This theory was selected as the researcher is in agreement with most of the assumptions concerned in this theory.

2.6.1 The nature of the Navigating Unknown waters Theory

The theory of Navigating Unknown Waters (Duggleby et al., 2010) provides a better understanding of the transitions experienced by advanced cancer palliative care patients and their families, as well as the psychological processes involved in adapting to these transitions. This theory is intended to help health care providers provide the service and assistance to patients and their families in this vulnerable time and stipulates the importance of the individual and staying connected with the community.

Duggleby et al. (2010) postulate that multiple transitions occur in the environmental, physical and mental health, roles and relationships and activities of daily living of the patient’s and family`s lives. Environmental transitions occur because the home of the patient and the family needs to change to adapt to the increasing physical limitations of the person with the advanced disease. Physical and mental health transitions are changes seen in an advanced disease patient, whilst physical limitations increase the more advanced the disease becomes. The mental challenges faced are the decrease in mental

health due to disease progression which sometimes involves brain metastasis. Roles and relationship transitions occur when a family is threatened with terminal illness or death as the family is forced to renegotiate the roles of individuals within the family. Some will take the role of caretaker and the leader role will be taken over by a mother or older son when the father is the patient. Daily life activities transition involves all the aspects of the patient`s life that is changing. Patient and family members will not be able to continue as normal and patients will have to give up work. Some patients even become bedridden. If a family member is the primary caretaker, their daily activities will change to taking care of the sick patient.

All of these transitions result in severe change in the lives of the patient and the family. The patient and family deals with this through the process of “Navigating Unknown Waters” which includes three sub processes: coming to terms with the situation, connecting with others, and redefining what is normal.

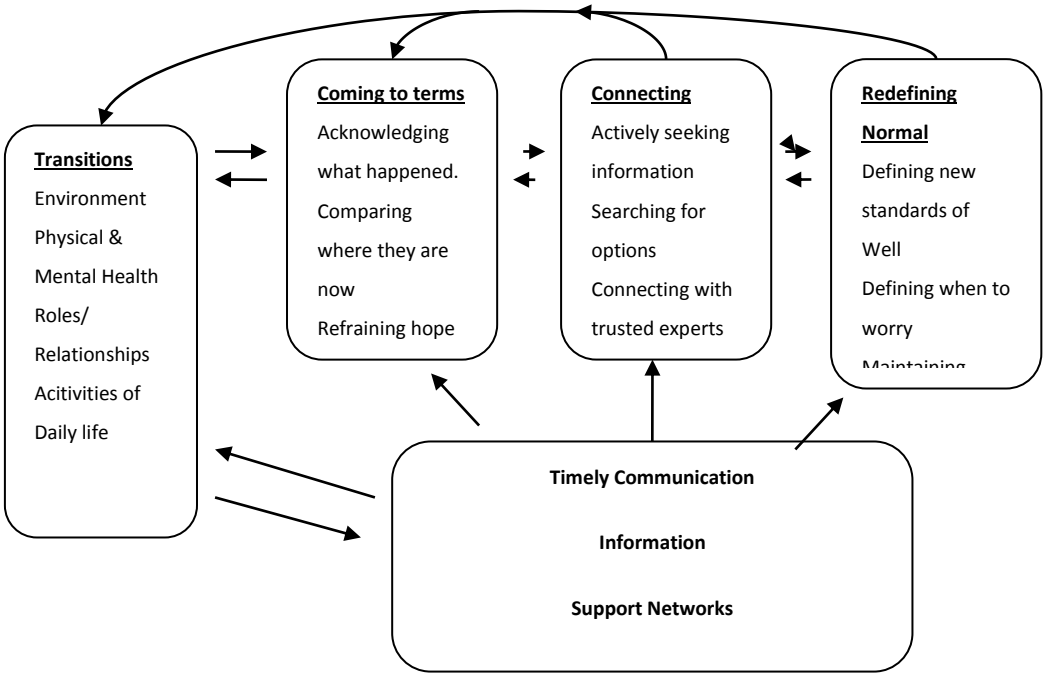
The first sub process, coming to terms, means to acknowledge what has happened. The patient and caregiving family member needs to negotiate and cope with a terminal prognosis. They also have to reminisce or compare where they are at that very moment. Palliative patients use life reviews and reminiscing as a way to transform hope. The family needs to reframe hope by managing their awareness of their situation through reframing their hope and setting their goals differently and focus on a good quality of life during end of life. The second sub process, connecting with others, involves actively seeking information on what to expect when the disease progresses after having acknowledged their situation. The family starts searching for options in caretaking and symptom management, where they will find some will work for them and some will not. Lastly the family caretaker will connect with trusted experts. Caregivers and patients seek out information from whom they consider experts. In this situation the palliative care nurse is considered an expert and the family care-taker seeks advice from her to optimally take care of their loved one. The last sub-process is to redefine normal, meaning the family needs to redefine new standards of well. This means palliative patients and their families change what they see as normal. Feeling normal for being sick is a new standard of well. This also means they need to know or to define when to worry. When they establish what being well was in their situation they are now able to identify when they should worry and seek professional help. Lastly the patient and the family caretaker needs to maintain personhood and involves that in the process of redefining normal, maintaining who you are, is very important. The patient is sick, but the patient and the family are still themselves and dealing with change (Duggleby et al., 2010).

There are certain factors that facilitate all these processes and sub-processes to take place. The first of these factors are timely communication where the patient and the family feel they are informed on what is going to happen, before it happens, which makes it easier to adapt. This includes expected symptoms and deteriorating of the patient. The next factor is the provision of information. The patient and family should be truthfully informed on what to expect when the disease progresses. The last factor facilitating these processes is support networks. A support network of friends and family is beneficial and can help to relieve the stress of caretaking by sometimes helping out or running some errands for the family caretaker (Duggleby et al., 2010).

In summary, the processes of the emerging Navigating Unknown Waters theory are interrelated and overlapping with constant interaction. The first process requires the patient and the caretaking family to come to terms with the situation. When they come to terms with their situation they are then able to connect with others and redefine what normal is for them in their current situation. To normalise their transitions will help them to adapt which will cause less stress and reduce uncertainty. Timely communications, provision of information and support networks are factors that facilitate these processes. These processes occur within the context of co-existing transitions, receiving palliative care and in dealing with advanced cancer (Duggleby et al., 2010).

The interaction and overlapping of the processes and the factors are illustrated in Figure 1. The arrows indicate the constant interaction and overlapping of the sub-processes. The processes are overlapping but for illustrative purposes they are depicted separate.

Figure 1. Navigating Unknown Waters (Duggleby et al., 2010)



2.6.2 Rationale for using the "Navigating Unknown Waters" theory

The rationale for using the "Navigating Unknown Waters" theory in this study is that it guided the researcher to explore the experiences of patients and families during one of the transition phases. The theory also shows the interaction of the processes that takes place while the patient and the family go through the changes to adapt to this new phase of their lives. All the processes involved assisted the researcher to fully understand what the patient and the family needs to go through while they transition from being a cancer patient receiving anti-cancer treatment to a patient where anti-cancer treatment is no longer feasible.

2.7 SUMMARY

Chapter Two presented a literature review of the concepts of the study. Cancer as a worldwide problem was described, followed by cancer treatment, the cancer experience, transitions in cancer care, caring for the patient and the family and lastly, a description of

the theoretical foundation of the study. Chapter Three will discuss the research methods and design of the study.

CHAPTER 3

RESEARCH METHODS

3.1 INTRODUCTION

Chapter 2 presented the literature pertaining to cancer, cancer treatment, patient and family experiences and care of the cancer patient and the family. In addition, the theoretical foundation of the study was also described. Chapter 3 will describe the research methods and design.

3.2 RESEARCH DESIGN

According to Grove et al. (2013) the research design is the set of logical steps taken by the researcher to answer the research question. An exploratory qualitative research design (Grove et al., 2013) was selected for the study. According to Grove et al. (2013) exploratory studies are designed to increase the knowledge of the field of study and are not intended for generalisation to large populations. Begley (2008) agrees with this statement and explain that exploratory research is primarily qualitative and conducted when little is known about the research topic or there is no definite answer despite previous work. The researcher selected an exploratory design as it is suitable for qualitative research and allowed the investigation of a topic which has not been researched in the South African context.

Qualitative research investigates phenomena in an in-depth and holistic fashion by means of the gathering of rich narrative materials. In addition, qualitative research is flexible and elastic allowing adjustments to what is being learnt during the course of the data gathering (Polit & Beck 2010). According to Finlay (2008), qualitative studies aim to create an understanding from data as the analysis proceeds. In addition, qualitative research tends to be holistic as researchers strive to understand the whole and requires researchers to become deeply involved by remaining in the field for lengthy periods of time. Qualitative research requires of researchers to analyse data in an ongoing manner to determine when the field work is completed (Polit & Beck 2010).

Using an exploratory qualitative research design allowed the researcher to explore and summarise the phenomenon of how a patient experiences the transition from palliation with anti-cancer treatment to palliation without anti-cancer.

3.3 RESEARCH SETTING

Burns and Grove (2009) define the setting of the study as the place where the study is conducted. The study setting was an oncology unit in the Southern Cape forming part of the private health care sector serving approximately 20% of the South African population (SouthAfrica.info 2012). This private cancer care setting provides comprehensive cancer care to people living in the Garden Route and Southern Cape; also in the regions between Albertinia and Mosselbay, George, Plettenberg Bay, Oudtshoorn and Union Dale. The Southern Cape hosts many retirement villages as this is a popular area for people to retire.

Patients are treated with radiotherapy and chemotherapy and a multi-professional team. This 25 member team consists of oncologists, oncology nurses, registered nurses, therapeutic radiographers, medical physicists and an oncology social worker. The majority of patients treated at this unit are diagnosed with breast cancer, colon cancer and lung cancer; many of them senior citizens. Approximately 800 patients are treated with radiotherapy each month whilst 350 are treated with chemotherapy; most of them have medical insurance, although some pay for their treatment privately.

3.4 POPULATION, SAMPLING AND RECRUITEMENT

According to Brink (2007) the population and accessible population differs in one or more aspect. The population refers to the population that the researcher has access to whilst the accessible population refers to the population actually studied. When defining the population, Grove et al. (2013) do not differentiate between the population and accessible population, but includes that the population can also be referred to as the “target population.” The target population for this study was patients and their families at the oncology unit in the Southern Cape, who were in the process of transitioning from palliation with anti-cancer treatment to palliation without anti-cancer treatment.

The researcher was practising as a registered nurse in the specific oncology unit and recruited the participants. Patients terminating anticancer treatment were contacted, the study was explained to them and they were invited to participate; they also received a

consent form outlining the purpose of the study. Time was allowed to consider the invitation where after they were contacted to enquire about their decision. An appointment was made with those who agreed to participate in the study. The family members who were the known primary care giver of the participating patients were contacted in the same manner.

As not all patients and their families could be included in the study, the following inclusion criteria were applied:

- Patients 18 years and older who were in the process of transitioning or who transitioned to palliation without anti-cancer treatment.
- A family member, 18 years and older of such a patient.
- Willing to participate.

Purposive sampling was used to select the sample. According to Brink (2007) this technique is based on the judgement of the researcher regarding subjects that are representative of the study phenomenon. Polit and Beck (2010) describe purposive sampling as a strategy where the researchers choose the participants who would best contribute to the information needs of the study. In addition to using a purposive sampling method, the researcher applied a typical case strategy referring to the selection of participants who would exemplify what is typical or average (Polit & Beck, 2010) in terms of the phenomenon under study.

Data saturation determined the sample size. Data saturation is when no new topics can be identified by conducting more interviews. This is seen when topics are repeated in new interviews and no new topics can be added. As already mentioned, stopping interviews when data saturation is reached is appropriate when qualitative work is done (Polit & Beck, 2010).

Eighteen participants, nine patients and nine family members, which were the primary care giver of the patient participant, were recruited for the study. Not all of those recruited were interviewed. Two patient participants were too sick at the time of the interview and two family members were unavailable. The two patient participants who were not interviewed was in a stable condition when the appointments for the interviews were made. However, at the time of the interview the researcher deemed them too sick to be interviewed. All of the participants were able to communicate in English or Afrikaans and there was no need for an interpreter during any of the interviews.

3.5 DATA GATHERING

Data gathering was described in terms of data gathering method, the data gathering instrument, pilot study and the planning of data gathering.

3.5.1 Data gathering and instrument

Self-report data were gathered from March 2013 to October 2013 through qualitative interviews. Self-report is any test, measure or survey that relies on the individual's own report of their symptoms, behaviours, beliefs, attitudes or other psychological variables (Salters-Pedneault, 2011). Additionally, qualitative interviewing can be used to answer research questions of immediate relevance to the researcher`s everyday work (Britten, 1995) thus underpinning the use of this approach in the current study. According to Brink, Van der Walt and van Rensburg (2006), the most effective method to find out what people believe, think or know is to direct questions to the persons concerned. The advantages of qualitative interviewing are that the researcher is able to explore the behaviour or experience of the patient and also find out about their opinions, beliefs, feelings, knowledge, sensory and background or demographics. Britten (1995) reminds the interviewer of the importance to maintain control of the interview and ask the right questions to get the information needed and to give the correct verbal and non-verbal feedback to the patient.

The researcher planned to use an interview schedule (Addendum C) to direct the interviews after gathering demographic data first. In the demographic data section the patient was asked what their diagnosis was, which was verified using the patient`s file. However after pilot testing the interview schedules (Section 3.5.3), the researcher used two opening questions – one for the patients and one for the family members. The opening question posed to the patients was: '*Please tell me what you experienced from the time you learnt that the anti-cancer treatment cannot be continued until now?'* and, for the family members '*Please tell me what you experienced when learning that (patients name) anti-cancer treatment cannot be continued until now?'* Thereafter the researcher used probes and prompting questions (Polit & Beck, 2010) to get an in depth understanding of experiences of the participants. According to Ritchie and Lewis (2003) probing in interviews is used to find reasons and allows the researcher to find explanations for the views, feelings, behaviours, events and decisions made by the participants (Ritchie & Lewis, 2003).

Data gathering was planned as follows:

- Permission to conduct the study was obtained from the Post Graduate Committee and Human Ethics Committee Research Committee (Medical) of the University of the Witwatersrand and the Ethics and Executive Committee of GVI Oncology (Addendum E & F). The Practice Manager of the specific cancer setting also supported the study.
- The researcher had been practising as a registered nurse in the chemotherapy department for six years prior to collection of data and was familiar with the setting.
- The researcher recruited all people meeting the inclusion criteria from March 2013 to February 2014 and invited them to participate after explaining the study to them. Informed consent (Addendum A & B) was obtained from those who accepted the invitation for participation in the study and voice recording (Addendum A^1 & B^1).
- Interviews were conducted at the patient`s homes All interviews were conducted in a private room where the researcher and the participant could communicate freely without disturbance and interruptions and lasted on average 50 minutes.
- The interview process and use of the voice recorder were explained before recording began to avoid confusion during the interview.
- Patients were reassured at the beginning of the interview that their anonymity would be maintained and confidentiality upheld.
- Demographic data were collected before the interview.

3.5.3 Pilot Study

According to Polit and Beck (2008), a pilot study is a trial run for the upcoming full study. The researcher used a pilot study to test the topic guide, the data analysis method and the use of a voice recorder. The first patient and family member interviews were used for the pilot tests.

The researcher had to change the opening question as the initial questions of the patient participants and those of the family members outlined in the interview guides did not answer the researcher`s questions on what they experienced when anti-cancer treatment was stopped. The first patient and family member interviews used for the pilot test were not included in the analysed data.

3.6 DATA ANALYSES

Open coding, using Tesch's approach (Creswell, 1994), analysed the data (Addendum D). According to Holloway & Wheeler (2002), open coding is the process of breaking down and forming concepts from the data. Data analyses commenced after the first interview allowing themes to be generated from the data. The data were analysed manually. The data were analysed as follows:

- The interviews were transcribed verbatim, printed and carefully read through to get a sense of the whole. Thereafter the interviews were reread and the researcher noted ideas that came to mind in the margin.
- Topics were identified and written down. Similar topics were grouped together.
- The topics were grouped to form categories.
- The interviews were read through again to see if any topics were missed and if any new categories emerged.
- The categories were grouped into themes and descriptive wording was used to name them.

3.7 TRUSTWORTHINESS

Trustworthiness is an important concern throughout the research process as it speaks of the rigour of the study. The guidelines of Lincoln and Guba, as summarised by Shenton (2004), credibility, transferability, dependability and confirmability were used to improve the trustworthiness of the findings of the study. Credibility is ensured by conducting the study in such a manner that the credibility of the findings is enhanced and that there are steps in place to demonstrate credibility to external readers (Shenton, 2004).

Credibility was enhanced by using well established research methods. In addition, the researcher perused the literature on the same topic to make sure all was of a qualitative nature. An early familiarity between participating organisations was ensured as the researcher has been practising as an oncology nurse in the same cancer care setting for six years prior to the gathering of the data. The participants were reminded there was no right or wrong answers to enhance honesty. Iterative questioning was used as the same question was asked in a different manner whilst interviewing the participants. Frequent debriefing with the supervisor was done to ensure the researcher`s developing ideas and interpretations were appropriate. Peer scrutiny was applied by handing a copy of the proposal of the study to colleagues and oncologists in the cancer care setting. By doing

this the researcher ensured assumptions that were made were correct. Member checks were done when the interviewer summarised what she understood of the interview and checked with the participants if she understood correctly.

Dependability refers to the reliability of the data over time (Shenton, 2004). Dependability was enhanced as the study was reported in detail and included all processes, design and implementation, operational detail of data gathering and a reflective appraisal of the project. Transferability refers to external validity allowing the study to be applicable to other situations or wider populations (Shenton, 2004). The researcher enhanced transferability by using purposive sampling and the description of eligibility criteria and if the same sampling method and criteria were to be applied in a different setting or larger population the same results would be achieved.

Lastly, confirmability, referring to two or more independent individuals being in agreement of the accuracy, relevance and meaning of the data (Shenton , 2004) was enhanced by coding the data, having the data audited by an independent coder, which in this case was the supervisor of the study and establishing and audit trail.

3.8 ETHICAL CONSIDERATIONS

According to Brink (2006), there are three fundamental ethical principles that guide the researcher namely: respect for persons, beneficence and justice. These principles are based on the human rights which need to be protected in research, namely, the right to self-determination, privacy, anonymity and confidentiality, fair treatment and being protected from discomfort and harm. Anonymity was enhanced numbering the interviews and using pseudonyms. Confidentiality was maintained by interviewing the participants in private. In addition, the following principles applied to this study:

- Informed consent was obtained before participation in the study. The participant had the right to decide voluntarily whether to participate in the study. A separate consent was signed for audio-recording the interview (Addendum A, A^1 , B and B^1).
- Participants had the right to withdraw from the study during the interview process and before the data had been transcribed. Once the data were analysed and synthesised individual participant's information could not be extrapolated from the grouped thematic analysis and withdrawal was therefore not possible.

- Although the participant's name was used during the interview, anonymity was protected through numbering the transcribed interviews sequentially.
- No harm was intended. Due to the sensitive nature of study, emotional discomfort could have been experienced. No specific measures was taken to prevent emotional discomfort, however, the researcher, a registered oncology nurse, equipped to address any anxiety or distress that the participant experienced, interviewed the participants. In addition, the oncology unit has the available services of a social worker and the patient or family member could be referred for counselling, which is free of charge for both patients and family members. None of the participants indicated the need to consult with the social worker during or after the interviews.
- Patient participants could experience physical discomfort during the interview due to the extent of their disease. Participants were assessed before the interview to determine any physical discomfort and the necessary nursing interventions were performed to enhance comfort. If discomfort was severe the interview could have been rescheduled. None of the participants requested the interviews be rescheduled.
- To ensure privacy, the interviews were conducted in a private room with only the participant and the researcher present. Time was allowed for the participant to raise queries.
- All participants who met the inclusion criteria were approached and invited to participate in the study. Data were only gathered until saturated.
- All data were saved on a flash drive before it was deleted from the computer where data was originally captured on. The flash drive is stored in an envelope with all the paper documentation and kept in a locked cabinet at the Department of Nursing Education and will be destroyed three years after the findings of the study have been published.
- The study approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand as well as the Ethics Committee of the private cancer care setting (Addendum E & F).

3.9 SUMMARY

Chapter 3 was a discussion of the research methods in terms of setting, population, data gathering and analyses, trustworthiness and ethical considerations. In Chapter 4 the findings of the research will be presented and discussed.

CHAPTER 4

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

In Chapter 3 the research methods were described. In Chapter 4 the findings of the study will be presented and discussed.

4.2 THE PARTICIPANTS

Eighteen (18) people participated in the study - nine patients and nine family members. Eleven patients and eleven family members were recruited for the study, however two patients were too sick at the time of the interview and only the family members were interviewed. Similarly, two family members were not available at the time of the interview and the researcher only interviewed the patient. Eleven of the participants were residing in the Southern Cape and seven resided in the Klein Karoo.

4.3 THE PATIENT PARTICIPANTS

The patient participants were primarily Afrikaans speaking and male. The ages of the participants ranged between 58 and 81, with an average of 70 years. The general information of this group of participants are presented in Table 4.1

TABLE 4.1 General information of the patient participants (n=9)

Variable	**Number of participants**
Age	
40-49	0
50-59	2
60-69	1
70-79	5

80-89	1
Home language	
Afrikaans	7
English	2
Gender	
Male	5
Female	4
Educational level	
Grade 8-10	3
Grade 11-12	3
Tertiary	3
Marital Status	
Married	6
Divorced/Separated	0
Single	0
Widowed	2
Living with life partner	1
Cancer diagnosis	
Prostate Cancer	2
Breast Cancer	1
Mesothelioma	1
Ca Bronchus	2
Ca Ovary	1

Renal Cancer	1
Colon Cancer	1

The following is a brief introduction of the participants:

JACK

Jack was an 81 year old man who was diagnosed with renal cancer in 2012. He resided in a town in the Southern Cape, but initially received treatment in the North West Province where his son practices as a medical doctor. After receiving three cycles of chemotherapy, he decided to move back to his home and continued treatment there. He stopped chemotherapy, in agreement with his doctor, due to side effects. He has two adult children. He lost his wife to pancreatic cancer. He was being cared for by one of his son`s and daughter in law who moved in with Jack.

LYDIA

Lydia was a 65 year old woman diagnosed with ovarian cancer in 2010. She has been living alone most of her life since her husband worked overseas on a contractual basis. She has two adult sons. One son lives overseas and the other one in Johannesburg. She had two dogs that played a big role in her life. Since she was terminally ill, her husband was at home and he was the primary caregiver to her.

TIMOTHY

Timothy was a 58 year old male diagnosed with advanced prostate cancer in 2001. At the time of diagnosis he had skeletal metastasis. Since then he had various different chemotherapy regimens and also received radiotherapy. Timothy is retired and married to his second wife. Timothy has two children from his previous marriage and two grandchildren, while his wife had two adult children from her previous marriage.

ANNA

Anna was a 75 year old woman with bronchus cancer. She was diagnosed in 2011 and received six cycles of palliative chemotherapy. She completed a course of 30 fractions of radiotherapy. Anna had four adult children; she lost her oldest daughter to suicide six years ago. Anna's second daughter lives in another African country, but her two sons live with her and her husband. Her primary caretaker is her husband who has been diagnosed

with early Alzheimer's, but they receive support from Cansa, their sons and general practitioner.

KATHY

Kathy was a 75 year old woman with lung cancer. She was diagnosed in May 2013 and treated with radiotherapy and one regime of chemotherapy, but after three cycles the chemotherapy was stopped because of her poor physical condition. She lost her husband 15 years ago after a long marriage and has three adult sons. She stays in Johannesburg, but her children decided it would be better for her to receive treatment in George, where her middle son resides and they can take care of her.

WILLIAM

William was a 72 year old man, diagnosed with prostate cancer in 2007. William, for some unknown reason, did not receive treatment after being diagnosed and presented with backache and a marked elevated PSA in 2012. He was diagnosed with advanced disease having had metastases to his bones and palliative treatment commenced in 2012. William was married and lived in a security estate with his wife who is his primary caregiver. He retired in 1994 and has two adult children.

FRANK

Frank was 77 years old. He was diagnosed with prostate cancer in April 2010 and locally advanced sarcomatoid mesothelioma in May 2010. He received 22 fractions of palliative radiotherapy for the mesothelioma and brachytherapy for his prostate cancer in 2011. He is married and his wife has been his primary caregiver.

CARL

Carl was a 58 year old man with metastatic colon cancer diagnosed in 2012. He had 30 weekly chemotherapy sessions, which he completed November 2012. No further treatment was offered. He lived with his life partner who was his primary caregiver. He had two adult children from a previous relationship.

ALICE

Alice was a 76 year old woman diagnosed with breast cancer. She was diagnosed in March 2012 and had a mastectomy. She underwent six cycles of chemotherapy followed by radiotherapy. In February 2013 it was discovered the cancer had spread to her cerebellum. She refused palliative radiotherapy. She has two adult children, of which one

daughter takes care of her and is her primary caregiver. Alice and her husband were married for 50 years.

4.3.1 Themes arising from the data

Four themes arose from the data: reaching the end of the anti-cancer treatment road, receiving support, living with the physical consequences of terminal cancer, coping with impending death. Each theme consisted of several categories which are presented in Table 4.2.

Table 4.2: Themes and categories arising from the patient interviews

THEME	CATEGORIES
Reaching the end of the anti-cancer treatment road	• Shock when learning that anti-cancer treatment would no longer be of benefit. • Fear and uncertainty about the future. • Reaching the end of the known. • Reflection on prior chemotherapy. • Thoughts of euthanasia. • Seeking alternative methods of healing. • Being failed and abandoned. • Spending the time left. • Experiencing sadness.
Receiving Support	• The family as the support structure. • Receiving support from friends. • Support received from Cansa.
Living with the physical consequences of terminal cancer	• Loss of independence. • Experiencing pain. • Experiencing other symptoms.

Coping with impending death	• Accepting the situation. • Fear of suffering. • Maintaining hope.

THEME 1: REACHING THE END OF THE ANTICANCER TREATMENT ROAD: *"I WAS SO SHOCKED"*

Shock was the overwhelming reaction of most participants when learning that anti-cancer treatment would no longer be of benefit to them. Their shock and despair was experienced as *"nothing can be done"* and the *"last way out."* Anna was so shocked that she was unable to speak for the whole day, she described her experience:

"…you know, I did not say one word… I did not cry, I could not…I can't remember that I said one word that day, I was so shocked…"

Timothy added: *"…this for me was a shock…it is umm, as if it was not the last way out…you immediately want to know how long you would still be spared…how long are you going to live…"*

William said: *"…no, it was quite a shock…it was."*

Learning that *"nothing can be done"* lead to desperation. Participants were scared and uncertain about the future and what they might be experiencing. Some were even too scared to ask the oncologist what they could expect. Timothy explained:

"…Yes, one is indeed scared…you don't know what is waiting for you…First it is a terrible shock and then there is some kind of acceptance…but still fear too…"

William expressed his fear and desperation: *"What are they going to do... what are they going to give …give morphine?"*

Frank said: "*I have not asked him yet because I am too scared. I will rather just go on like now and see what happens and see what the doctor will do."*

Not being able to receive additional cancer treatment meant the end of the known and having to face the unknown. In addition, participants were confronted with their own death and the fear surrounding death and dying. Lydia said:

"*I am scared of dying…I suppose everybody is…it is only human even if you are religious…"*

Kathy said: "*It is where you are faced with the unknown and don't know what lies ahead, and it is unknown what you are going to experience. You are scared, anyone would be scared…I am scared of being alone…"*

Learning that additional palliative chemotherapy was not indicated forced participants to reflect on their chemotherapy experience. For some receiving palliative chemotherapy was a positive experience whilst others experienced it negatively. Being informed of the possible side effects of the treatment could not prepare participants for this experience. Anna said: *"…despite being nauseous, it was better than I thought it would be…"*

Kathy said: *"…yes, and then you go for chemo…and then you go for radiotherapy…yes, it is the effects that you are going to have…and then, boom, it happens…it is like someone throwing cold water in your face…"*

Alice said: *"… I was very disappointed in the treatment…"*

Some participants wished they could continue with chemotherapy despite the side-effects, whilst others expressed relief that the chemotherapy had been stopped. Lydia said:

"*I don't know…I think it's the thought of those needles. It is not the staff …I mean the staff has been marvellous. It is just me. Also once you experienced the after effects, then you realise what you are going to be going through. That is why I am pulling my face right now… the thoughts of that nausea and things like that, but umm I got through it… and then came a couple of what I like to call decent days…but not good days, they would just be a little better than the day before. Wish I could have those now, because I feel worse now than what I was when I was on the chemo…"*

For Jack, stopping the chemotherapy was a great "relief"; he said: "*You stay nauseous all the time, you don't have any strength, and you can`t do anything. .. After the chemo was stopped I regained my strength and I can do things around the house now."*

Euthanasia seemed to be the way out for some participants as they could not face being terminally ill and being dependant on others. Timothy said:

"*I am not necessarily afraid of dying, but I don't want to be bedridden and so weak that I can't do anything for myself. That is why I have said so many times I can be an advocate for euthanasia."*

William said: "*My daughter asked if I can't have an injection for my pain, and I told her I don't need an injection for pain I need to be taken to the vet…"*

The fear, desperation and uncertainty about the future resulted in seeking alternative methods of healing; some even believed they could still be cured. Alice said "*I still believe I can be cured*…" whilst Lydia explained the alternative treatment she was receiving in the hope to be cured:

"...*you get these two metal goodie things and you sit there in a chair with your feet flipped up and a blanket over you … I just sit there... I am just holding these two things with my arms rested up here, one can be for up to an hour, another can be for up to half an hour. This cleanses the liver, the kidneys, the cancer. The only thing with this is you don't get a pre count so you don't know how it is working."*

Participants experienced the cessation of the palliative chemotherapy as being failed and abandoned by the health care team caring for them. Reaching the end of the chemotherapy road resulted in them being referred to other care teams providing palliative home based care; ending their relationship with the known and trusted. Lydia said:

"It just feels as though you have just been left out...it is if there is nothing else we can do, left high and dry… My husband always asks 'Where is this counsellor that you suppose to have there (at the oncology unit), that`s supposed to be there for you?' and I say 'I don't know, busy doing something… I don't know'."

Anna added: *"You build a relationship with that person, and yes, you don't see that person again, you know… it`s just goodbye and they give you a hug..."*

Frank said: *"…it felt like the doctors didn't take much interest in my cancer anymore…"*

Realising anticancer treatment would be of no further benefit resulted in participants reflecting on what they still wanted to do, how they would spend the time left for them, what would be possible and what would not. Anna said:

"I will spend my days doing much better things; enjoying the birds, flowers, wonderful birds and nature. I would have loved to visit my daughter once more."

Lydia said: "*I may never see that apartment again. I can't travel you see. The problem is I am in so much discomfort that I can't seem to travel. I mean I would like to go up there, it`s tiny and compact…you are overlooking the harbour and the sea so you`re in a different world again. So really, when you look around you, you`ve got the flowers and things like that and you`ve got the dogs."*

Kathy added: *"…I need to go home once more…I need to divide and give away all my worldly possessions…my husband and I worked so hard for it, you know it is beautiful furniture that I have and I just want to go home once more and get to divide and give away my things.… I hid from them that I have been coughing up blood lately, because I am scared that they won't allow me to go home once more."*

Participants experienced a lot of sadness. Some were able to share their thoughts about death with their family and friends, whilst others could not. Timothy said:

"Sometimes when I am down I phone one of my friends and then we talk about death…about death…about death, and umm I think it is more about getting ready because you never know when it's going to happen."

Anna could only talk to God about death, she said: "…*we all want to live. When I am very sick at night I ask God, only one more night please!* (weeping)*."*

Lydia said*: "I love to see the flowers and the shrubs growing and the dogs are always beside me, and it is that… but all and all I cannot talk about leaving David and the dogs."*

William added: *"…my wife, we don't really talk about it (weeping) but she takes care of me…"*

Participants were shocked when they learnt that palliative chemotherapy was of no benefit any longer. They were scared of the unknown the future held and what they might be experiencing. They were confronted with their death and scared to die. For some, euthanasia seemed a good option, whilst others believed they could still be cured and used alternative therapies in the hope of a cure. Participants experienced a lot of sadness and felt failed and abandoned by the health care team who cared for them.

THEME 2: RECEIVING SUPPORT: "*SHE IS THE LIGHT IN MY HOUSE"*

Support played a major role in the lives of the participants. Participants received support from various sources including their families, the church and the Cancer Association of South Africa (Cansa). Most felt they were well supported however, suffering from cancer, a long and protracted disease, resulted in a decrease in support with time. Frank said:

"Wherever we go I tell everyone that if it was not for my wife, I would definitely have been depressed. I would have...I don't know, my life would not have been the same without my wife."

Carl said: *"My partner is a very good person and this is a very heavy burden for her, but she also made peace with it and she is supporting me and we will walk this road together."*

Jack responded: *"If I must tell you what support I got from these two kids! They left their house just like that, packed up their work and moved here to support me. I have a daughter in Namibia who has been here four times since December and that is far!"*

Timothy was not so lucky and described how the support he received from his friends diminished over time: *"The first time that I heard I have cancer everyone pampered me and everyone was so worried about me, but over the years people sort of forgot about me…the cancer is not gone, it is still there. It is as if I receive less attention. It is not that I am seeking attention it is just when I say I have pain; people think I am pretending....When friends come to visit for the weekend they expect me to spend the same time with them as before I was sick, but that is not physically possible for me anymore. They don't understand… it seems like they are thinking I could have tried to stay a bit longer."*

Lydia did not receive any support when receiving her chemotherapy due to her husband's work; her sons were also not supportive. She said:

"All the time while I was going through chemo I was all by myself, because my husband was away five weeks at a time. I got through all that... As for the sons, we don't see the sons a lot…"

Participants were also supported by members of their church and Cansa. Alice said: *"I can`t complain about the support, the people of our church has been very good to us."*

Jack said: *"All my friends are from the church. No, I can't complain about the support I've been getting."*

Anna described the support she received from a member of Cansa: *"Melany is the one that comes to our house; she is the light in my house. She's got that personality, she lights up everything when she comes in through the door. I think it is because she's been doing it for years. She knows my whole house."*

Carl said: *"Melany from Cansa regularly visits me and my kids come here often. We all carry this burden."*

Support played a major role in participant's lives and the people who supported them help with carrying the burden of their terminal disease. Some were supported by their family

members, the church and CANSA whilst others had to cope on their own. Support also diminished with the lengthy disease process.

THEME 3: LIVING WITH THE PHYSICAL CONSEQUENCES OF TERMINAL CANCER: *"IT NEVER STOPS PAINING HERE"*

Participants feared they would lose the ability to care for themselves and would have to depend on others. Some participants did not want to burden their families when they got to the point of being dependent on care and preferred to be cared for by others. Timothy said:

"I think my biggest fear at this stage is that I am going to get very sick and that I umm... how shall I put this?.. get bedridden, that type of thing before I just totally disappear…I don't want to…I don't want to be totally dependent or so sick that I can't take care of myself."

Kathy preferred not to burden her family with caring for her and said: *"I felt comfortable in hospital. You don't feel so guilty to ask for help from the hospital staff. It is better than to have your kids rush out at night."*

Participants experienced a large symptom burden which included pain, nausea, anorexia, constipation and fatigue. Pain had a major influence on the quality of life of the participants. For some pain control was a reality, while others felt they never got any relief.

Timothy said: *"Yes about the other things like pain.., I think the pain medication I am using has got my pain under control, I really think so."*

Carl said: *"At first the pain medication did not help, but they increased the strength and now it helps and I made peace, because I can now walk around again and I am not lying in bed all day and I can do things for myself."*

Lydia was not as lucky as Timothy and Carl, she was in constant pain. In addition, the side effects of the prescribed analgesics made it impossible for her to take it as prescribed. She explained: *"...it never stops, it never stops paining here and here (points to her abdominal area). I can hardly get in and out of bed. I can hardly get into the bath, I have to lift my leg up, and I am so skinny but that`s beside the point, and this is so uncomfortable. Can`t get any relief, you know if it was a little baby growing in there, and if I was a little younger I would go oooh (hugs her stomach), but this is SO uncomfortable* (weeping)…*too strong painkillers I can't take, it makes me go peculiar. I don't know what it*

is, myself and the doctor had a laugh over it and he said you know what you are like with the strong painkillers. He said I can take up to twelve pills per day. I take six per day even in the beginning when I use to take other pain pills, I took one not two, because this pain will not let go. Then I am saying to myself it's because I am not having any treatment..."

William added: *"The pain is so uncomfortable that I don't know what to do. The doctor said he can give me pain pills. So he gave me some. Those pills made me extremely nauseous. I couldn't eat anything, and if you can't eat, you can't take pills. So it's a catch 22.*

Some participants experienced nausea which influenced their appetite. William said: *"I have some of those pills that prevent nausea, I don't think it works, it doesn't feel like it. And that is where I am at this stage... I mean it`s the nausea, I can't eat."*

Anna explained that the nausea she experienced was related to fatigue. She said: *"I was very nauseous. It's a different type of nausea. It's when I am tired. I found that when I am tired I am nauseous...I was very sick three, four nights ago; I had a lot of visitors that day. I was so sick that night I couldn't sleep. The next day I phoned Melany from Cansa and she gave me an injection and I felt much better."*

Timothy experienced constipation, he said: *"The only thing that is really a problem for me is constipation, and until now I have not received any helpful advice from anyone about it."*

Participants feared losing the ability to care for themselves and being dependent on others for their care. In addition, they experienced a large symptom burden including pain, nausea, anorexia, constipation and fatigue. Pain seemed to be the most prevalent and debilitating symptom. Nausea was also a major problem, for some unrelieved, causing anorexia.

THEME 4: COPING WITH IMPENDING DEATH: *"HE MUST TAKE ME"*

Some participants seemed to cope with their impending death as they were able to accept it although not easily, whilst others had difficulty to believe what was happening to them. Anna said: *"You won't believe how you just accept this. At first I sat here. Golden Years is the name of the retirement resort across the street, and I know a lot of the people that walks around there. And then I would sit here and think, you know some of them are much older than me, and look at them being so active while I have to just sit here, but that feeling has totally gone away. That yearning is not there anymore..."*

Timothy said: *"Strangely with time it got more acceptable. I mean there are still times that...At first it was a huge shock, but then there is a sort of acceptance, but you are still scared."*

Lydia was one of the participants who found it difficult to believe what was happening to her and said: "*I don't think you believe that it is actually there or you actually have it. You know what I mean, well that's with me, even now I know I've got it, I know it's going to take me, but I don't know, I just cannot believe I've got it....Doctor S (psychologist) is a very nice man and very understanding, very caring. He said to me I've been going there because I am not ready. I don't feel ready to just sit there..."*

Despite being able to cope with their impending death, the fear of suffering was central to the lives of some participants. Anna said: *"I have a feeling that I won't suffer too much. It doesn't feel like it, it doesn't feel like I am going to suffer terribly. I'll tell you I have been so tired sometimes that I thought the end is near."*

William said: *"As I said my biggest concern is not necessarily being afraid of dying.., I don't want to be bedridden and so weak that I can`t do anything."*

Jack said: *"I know on the road ahead things will get worse, that`s how it works."*

Hope played a major role in the lives of the participants. Religion facilitated hope and helped participants to accept their impending death.

Jack said: "*There are three things that are very important; I am a child of God. I am a religious person. I believe that God has got his path that he is going to walk with us. From God I got my support.... My life is in the hands of God. That is all I'm holding onto and He will take care of me on this road."*

Kathy added: *"Umm and then I decided, because I am a religious person, if God brought this on me, then I accept it. Umm He's got grace, and if this is His way to take me, then He must take me. I have accepted it."*

Carl said: *"I don't know what the future may hold and I don't know how far the cancer will go, but I must live with it and accept it. God brought this over me and there is nothing I can do about it."*

Alice maintained hope by believing that she would be cured. She said: *"...but I believe that God is going to cure me, from today onwards He will cure me. The doctors have been very good to me...but I believe it's (cancer) going to be cured, and I believe that the pain*

medication is going to make me feel so much better, that I will be able to stand up and thank God."

Frank shared Alice's hope and said: *"At this stage I am living with the cancer. I ask God to control the cancer and not to let it grow anymore. My expectation is that the cancer will no longer grow. At this stage the cancer is no worry to me."*

Being confronted with impending death was not easy. Some participants were able to accept it whilst others denied they were terminally ill. Participants feared the future and feared they would suffer during their last days. Their belief in God brought comfort and hope to some and they believed God would carry them through their last days. Some participants maintained hope that they would be cured.

4.4 THE FAMILY PARTICIPANTS

In addition to the patient participants, the family participants were also primarily Afrikaans speaking. The ages of these participants ranged between 31 and 83, with an average of 55 years. The general information of this group of participants is presented in Table 4.3, followed by a succinct history of the family members and a summary of the relationship between the patients and family members (Table 4.4)

Table 4.3 General information of the family participants

Variable	**Number of participants (n=9)**
Age	
30-39	1
40-49	4
50-59	1
60-69	0
70-79	2
80-89	1
Home language	

Afrikaans	7
English	2
Gender	
Male	1
Female	8
Educational level	
Grade 8-10	1
Grade 11-12	4
Tertiary	4

MARY

Mary was 44 years old and the second wife of Robert. Robert, a retired engineer was 70 and diagnosed with Multiple Myeloma in 2011, who at the time of the interview was too sick to be interviewed. The couple moved from Kwazulu Natal to a picturesque town in the Southern Cape, as they were of the opinion they would have a better quality of life. Robert had two children from his previous marriage, one residing overseas and the other in South Africa, but not close to where he lived. Robert did not participate in the study because he was too ill at the time of the interview, only Mary was interviewed. During the day, Lizzie, a caregiver, cared for Robert and Mary took care of him after hours.

DANIEL

Daniel (49) was one of Jack's adult sons. Jack was an 81 year old man who was diagnosed with renal cancer in 2012. Daniel and his wife moved to their father's house to take care of him. Daniel is an author of travel books and his wife worked with him. As they worked from their home they were able to pack up everything and move to this picturesque town in the Southern Cape and continue with their work. They moved in with Jack when he started treatment and were his primary caregivers.

THERESA

Theresa was 49 years old and married to Timothy, who was 58 years old and had advanced prostate cancer. She recently started a new, very demanding, career which keeps her busy during the day. Her husband stays at home when she is at work. Teresa is Timothy's primary caregiver and she needed to take time off from work to bring him to the oncology unit. They have a very loving relationship and they enjoy the support of their children, although they are far away.

FIONA

Fiona (51) was the daughter-in-law of Kathy who was 75 years old and suffering from long term cancer. She works from home and takes care of her mother-in-law. She keeps the rest of the family informed on Kathy`s condition.

SUZY

Suzy, aged 70, was the wife of William who was 72 and had prostate cancer. She bought a new business and needed to spend time there in the mornings to make sure everything was in place. William stayed at home during the mornings, which was of great concern to Suzy. She struggled with the fact that he did not eat and relied on her daughter, who lived close by, to support her in taking care of William.

DEBRA

Debra was the 75 year old wife of Frank, who was 77 years old and suffered from prostate cancer and locally advanced sarcomatoid mesothelioma. They have been married for a very long time. Debra was a retired nurse and thus is the primary caretaker of Frank. They live in the Karoo. She enjoys the support of their adult children, friends and the church.

MEGAN

Megan was the 31 year old life partner of Carl, who was 58 years old and diagnosed with advanced colon cancer. The couple, living in the Karoo, had been together five years. Megan was the primary caregiver of Carl. They had been together for three years before he was diagnosed. Megan had no children of her own, whilst Carl had adult children from a previous relationship. She gave up her work to take care of Carl during his illness.

TAMMY

Tammy was the 46 year old daughter of Alice who was 76 and diagnosed with breast cancer. Tammy does not live in the same house as her mother but played a pivotal role in the support and care of her mother, as she was her primary caregiver during the day. Although Tammy had a family of her own she made time to see to her mother.

EMILY

Emily was the 83 year old wife of Dean, who was too sick to be interviewed. Dean was 82 years old and had been diagnosed with colon cancer in 2012. Dean received oral chemotherapy which was stopped after two cycles due to the side effects. The couple had three adult children. Emily was under tremendous stress during the time of the interview as they had sold their house and in the process of moving to an old age home. She was responsible for moving the household and caring for Dean who was bedridden.

Table 4.3 summarises the relationship between the patient and family participants.

Table 4.3 The relationship between the patients and family members

PATIENT	**FAMILY MEMBER**	**RELATIONSHIP**
Male patient too sick to be interviewed.	Mary (44)	Wife
Jack (81)	Daniel (49)	Son
Lydia (65)	Family member not available at the time of the interview	Self
Timothy (58)	Theresa (49)	Wife
Anna (75)	Family member not available at the time of the interview	Self
Kathy (75)	Fiona (51)	Daughter-in-law
William (71)	Suzy (70)	Wife

Frank (77)	Debra (75)	Wife
Carl (58)	Megan (31)	Girlfriend
Alice (75)	Tammy (46)	Daughter
Male patient too sick to be interviewed	Emily (83)	Wife

4.4.1 Themes arising from the data

Three themes arose from the data: learning that anti-cancer treatment is no longer feasible, having to care for the terminally ill family member and the important role of religion. Each theme consisted of several categories, which are presented in Table 4.4.

Table 4.4: Themes and categories arising from the family member interviews

THEMES	**Categories**
Learning that anti-cancer treatment is no longer feasible.	• Experiencing shock and disbelief. • Having to face the impending death of a family member and loved one. • Feeling abandoned by the staff of the cancer care setting. • Being satisfied with the referral process and support.
Having to care for the terminally ill family member.	• Experiencing uncertainty and fear. • Acute awareness of the deterioration of the family member. • The cost of care. • Support structures.
The important role of religion.	• Relying on God. • Hoping for a miracle.

THEME 1: LEARNING THAT ANTI-CANCER TREATMENT IS NO LONGER FEASIBLE: *"WE HAVE BEEN WRITTEN OFF"*

Almost all the family members experienced shock and disbelief when learning that their loved ones could no longer receive further anti-cancer treatment. Mary said: *"..well I mean I knew he was sick when he was hospitalised for two and a half weeks. I think the initial thing is shock…denial, you know, is this possible? But after his heart trouble you think anything is possible. So, yes it was like another medical hick up. That`s actually what it was."*

Suzy said: *"No it was a big shock. That's it. He (doctor) said it's a matter of three months to three years…"*

Fiona added: *"At first that disbelief, that you can't believe, is it really that bad?"*

For Debra her husband's cancer was initially difficult and sad, but a change in attitude made the fact that anticancer treatment was no longer an option not so difficult. She said*: "You know we've actually been very positive about it from the beginning. In the beginning it was sad, but after that it totally changed because we changed our attitude about it. It's a way of living now."*

After learning that anti-cancer treatment was no longer an option, the family members were forced to face the impending death of a family member and loved one. Some were able to talk about it, even though they knew that it was a difficult road ahead, whilst others could not even think about it. Fiona said:

"Yes, I know it`s going to get more difficult. With her it's going to get even more difficult. She gets impatient. Her memory is fading. Yes, we will just have to learn to be patient and just get the strength to get through this. Yes, I see a difficult time lying ahead of us, but yes that is where we are now."

Theresa and Suzy were not ready to face what lies ahead and did not want to think about it.

Theresa said: "*I don't want to think about it...I don't want to think of anything negative."*

Suzy added: *"Look he already planned all these things long ahead and already made provision for it. I haven't... I haven't. I am not at that stage yet where I want to think about these things. If he wants to do it and it makes him happy then its fine with me...if it makes*

him more comfortable. He has got this idea that I don't agree with, he wants to be cremated and he does not want a church service."

Mary felt unprepared and said: *"And the doctor said well like in a year, year and a half. And three weeks later he is in hospital and ten days later he is coming home to die* (weeping)."

Once additional chemotherapy was no longer feasible, the sick person was referred to Cansa or other organisations rendering home based care. Some family members were unhappy about how the situation was managed, felt abandoned and "written off" by the staff of the cancer care setting where their family members received treatment. Tammy said:

"It was definitely not done professionally, it was not explained to us as her family and we were there. My brother was here from overseas for ten days and nobody explained anything to him. I phoned the day before yesterday and they said they would phone me back, but they still haven't phoned back yet and my brother just wanted to talk to them a little. I don't know but I feel it was not handled correctly. I understand the doctors and specialists are very busy, but then they need a go between person between the doctor and the patient."

Mary said: *"Well it was like being totally deserted. You almost feel, as I`ve said before, that because you`re no longer making a profit to the practice, it`s almost a case of okay that`s you, thanks for your profit, but now you`re on your own…you know it really is. In terms of being out of hospital, after the physician spoke to the oncologist, whoever made the decision, but the feedback I got was that my husband could come home providing I don't phone every five minutes and if I had a problem I would take him to the emergency room. Now if that's not like washing your hands off the patient you served for two years, you know then what is? You know, that to me is wrong. And then also when he wanted the appointment and through whatever glitch he never had it, just another sort of feeling on our side…we`ve been written off."*

Not all the participants felt abandoned and unsupported and were satisfied with the referral process and support they received. Suzy explained: "*I have to say I have always felt comfortable to phone the unit. They gave me a card the last time we were there and said we can phone any time…"*

Fiona added: *"And I mean the doctor, wow, he is at the hospital half past five in the mornings, and still doing rounds at half past eleven at night. During the day when you leave a message, he phones you back even if it's half past eight at night. He phoned my*

husband on his cellular phone. You don't get that anymore. I really take my hat off to these doctors and the rest of the staff at oncology; it was an unbelievable road to walk."

Debra said: *"Look, cancer is pain in the end, but it is there and the medication is there that he can use. You know the doctors works nicely with us, we understand it and they change the medication on the report we give back to them. So we don't have any problem at the moment."*

Participants experienced shock and disbelief when they learnt their family member could not receive additional palliative chemotherapy. They were confronted with the death of their loved one and reacted differently to this reality. Some accepted the situation whilst others denied it by not wanting to think what was lying ahead. In addition, some participants felt let down and abandoned by the health care team who cared for them during their palliative anti-cancer treatment, whilst others were satisfied with being referred to palliative care teams.

THEME 2: HAVING TO CARE FOR THE TERMINALLY ILL FAMILY MEMBER: "I DON'T KNOW HOW."

Having to care for their loved one was a great challenge for the family members. Caring for a terminally ill person was unknown terrain, creating uncertainty and fear that they would not know how to do this, which resulted in helplessness. Fiona said: "*I mean I don't have a medical background, I have done a certificate with St. John`s but that`s basically it. And now I sit here with things I don't know how to handle…"*

Megan said: *"It sometimes feels as if nothing helps, sometimes the pain killers works and other times it doesn't, and then I`ll rub him with something…"*

Suzy said: *"I feel very sorry for him when the pain comes. I feel very sorry for him, I want to pick him up and nurture and I wish I can take the pain away and it hurts me so, so much (weeping)."*

Having to care for a terminally ill family member also resulted in an acute awareness of the deterioration of the sick person. Mary said: *"But it is hard to watch a person not be able to walk, turn themselves, sit up sit down, the shakes as the calcium levels rose and watching the death process."*

Having to meet the needs for care was not easy and also costly. Not all the participants had full medical coverage for these events and had for to wait for medical insurer's

approval to cover some of the costs and pay from their own pockets. Mary said: *"I did a cash transfer to one of the hospices. I mean they went to get authorisation for home nursing. Well that took three weeks. Three weeks after he got out of hospital, the medical aid approved home nursing. A bit late, but I was paying cash and I had them from seven until two in the day, Monday to Friday, the rest of the time I was coming home from work and I was basically nursing him from two in the afternoon till seven the next morning and weekends."*

Suzy said: *"I don't know if the doctor can prescribe it in such a way that the costs can go through the medical aid…the tablets is R70 or R80 a tablet and the generic one is about R40, and we can't have it through the medical aid...."*

In contrast, Debra was happy with the support they got from their medical aid. She said:

"I have to say the assistance we get from the medical aid is one of the big things in our lives…if we did not have it I don't know what would have happened. There is nothing that he can't have through them…there are a lot of things they don't approve which they know were not right for him or they will give a generic that is the same…we get good assistance from the medical aid."

The family members received support from various sources whilst caring for the terminally ill person, including other family members mostly children, friends, the church, Cansa and Hospice. Most participants were satisfied with the support they received, whilst others felt alone and abandoned. Suzy and Debra explained how they were supported by their children. Suzy said:

"Well our daughter is here every day. She moved back here from Gauteng... She comes regularly. Our son lives close by and he comes every Sunday, then we have a family gathering."

Debra added: *"You know our kids... we have lovely kids and we have a beautiful family bond. Everyone was here for Christmas; we were 15 people that day. Only our one daughter couldn't make it. And you know we get the best support from them."*

Not only family members, but also friends played a supportive role. Tammy said: *"There are a lot of people giving love that brings flowers, that brings snacks, who phones regularly and cares. I am amazed to see how many people. Even people who usually only greeted us, now comes and visit…"*

Knowing the sick person was supported by others made it easier for those caring for that person. Daniel said*: "I mean all his friends are here, that`s why we moved here...At this*

stage medical care is not the most important thing, support is most important. The fact that my father is receiving support from his friends and his family is making it easy for us."

Suzy added: *"All his golfing friends comes here regularly and have some coffee with him. Sometimes they want to come fetch him, but he doesn't enjoy that anymore."*

Not all the family participants experienced being supported by other family members, mostly due to the fact that most of their family was far away. Mary said:

"Family is all away so there is no family support and friends. No one came to basically assist with the care of him. There was like emotional support like telephone calls and I was chatting to close friends… in terms of support at home, none."

CANSA and Hospice supported families in caring for their loved ones. Debra said: *"And I must tell you if it wasn't for the visits from the Hospice sister, that always gives us hope, then I don't know what we would have done*."

Fiona said: *"From there I drove to hospice to find out what they have available and to find out where they are. They immediately told that they have a bed for my mother, and we were looking at a pillow for her that can assist her not to lie to heavily on her lunges. The sister gave me a shake for if my mother can't eat anything. You know those people are amazing, all that support was more than enough at that stage."*

Megan said: *"I get a lot of help from people. People come here and ask what they can do for us and his kids. CANSA helps a lot."*

Mary was however not so satisfied with the support they received, as she was not consulted and not kept informed. She said:

"A carer worked from seven till two, I did two until seven the next morning, I know what is happening, but I was never consulted. My input was never asked. I find that very strange, I mean my husband would comment saying the sister was here today, and I would check with the carer and she would say; 'o she just checked how he was doing and to check on his bowels.' And I would say I find it odd that she does not contact me, because I actually take care of him for longer periods and I know more. So that was a bit odd…"

Having to care for the terminally ill family member created emotional distress as some family members felt helpless about their care. The family also became acutely aware of the deterioration of the terminally ill person - a process difficult to witness. The cost of care was high and not all participants were financially supported by their medical insurance. Some participants were supported by various palliative care groups and their families but

others felt alone and abandoned. Receiving support lightened the burden of caring for the loved one and most participants were satisfied with the support they received.

THEME 3: THE IMPORANT ROLE OF RELIGION: "*I PRAY TO GOD EVERY DAY"*

Religion played a major role in the lives of the family participants and many relied on God to help them get through this difficult time and to prolong the life of the sick person. Megan said: "*I pray to God every day to give me strength to support him."*

Suzy said: *"God walks this road with us. Everyone we talk to say we are on borrowed time. So we have borrowed time to make things right."*

Theresa said: *"The thing is we stay on our knees and trust God, because there is medically nothing more they can do for him. And umm...just believe and trust that God will give him a year or more, you never know where He made lead us."*

Some participants hoped God could still cure their loved one, if that was His will. Some believed that miracles could still happen and others, like Tammy, were satisfied with whichever way God chose. She said:

"I was happy with the treatment she got, but if God decides He will cure her it's His time and His hands. But I believe if He takes her, and she also said so, she is ready to go when He is ready to take her... if anyone can cure her it will be God. And if that can't be then we want her to be comfortable and we are content with that."

Suzy said: *"I am now at this stage, I still see the light…I still believe that a miracle can still happen…I believe it with my whole heart. All that worries me is the fact that he has been losing so much weight. I have spoken to the doctor about it, but my personal opinion is that the doctors told us (nothing can be done), but God haven't told us that yet."*

God played a major role in participant's lives and they relied on Him to give them strength during this difficult time. Additionally, some family members hoped God would prolong the life of their loved one, whilst others still hoped that a miracle would happen and the terminally ill person would be cured.

In summary, both the patients and family members were shocked when they learnt that palliative chemotherapy was no longer feasible. Both parties described how they felt when confronted with death – either their own or that of their family member. Both the patients and family members experienced uncertainty and emotional distress when talking about

the unknown future. Patients feared they would suffer, lose their independence and become dependent on others for care, whilst some family members feared having to care for the terminally ill person because they felt unequipped. Patient participants mentioned euthanasia, whilst family members did not raise this possibility. Family participants raised the issue of the cost of the care which was not mentioned by patient participants. Both the patients and family members mentioned they felt abandoned and let down by the health care team who had cared for them during the time of palliative chemotherapy. For some the arrangements made for further care were acceptable. Support was important for both the family and family participants, as it spread the burden of being terminally ill and of caring for the terminally ill person. Patient participants experienced a high symptom burden, a situation the family was well aware of and which added to their fear of caring for the sick person. Although both groups of participants believed that cure was still possible, only patients referred to seeking alternative methods of healing. Religion played an important role in the lives of both the patients and family members and brought comfort and hope. Family members trusted God to support them during this difficult time, whilst patients trusted God to embrace them during their end of life journey.

4.5 DISCUSSION

As evident by "*shocked,"* both the patients and families experienced shock and disbelief when learning that palliative chemotherapy was no longer feasible. In addition, they feared the future and reaching the end of life as it was known to them. As illustrated by "*I am scared of dying,*" patient participant's feared death whilst family members feared the "*difficult time lying ahead.*" Whether the shock and disbelief of not being able to continue palliative chemotherapy are similar to that of learning of a cancer diagnosis is not clear as the literature does not seem to speak about this issue. In addition, literature describing the emotions patients' experience when learning anti-cancer treatment is no longer feasible does not seem to be available. However, Morita, Akechi, Ikenaga, Kizawa, Kohara, Mukaiyoma, Nakaho, Nakashima, Shima, Matsubara, Fukimari and Uchitomi (2004), in a study conducted in Japan focusing on bereaved family members of cancer patients who were receiving palliative care, found that 40% of family members experienced high stress levels when they learnt that no additional anti-cancer treatment could be given to the patient. Wong and Chan (2007) found that even though the family knew the patient had cancer they were shocked that the patient reached the terminal phase so soon and they had difficulty to accept it.

As supported by "*I am scared*," patient participants feared their impending death; they feared they would suffer, lose their independence and become dependent on others. In addition, as supported by "*I may never see that apartment again*" patients had to face various additional losses. Supported by *"I don't know how*," family members feared having to care for the terminally ill person. Finding that patients struggled with the thoughts of being a burden or dependant on others is supported by Roth and Massie (2007), who found a similar trend. In addition, finding that family members feared caring for the sick person concurs with what other caregivers' experience. Stenberg, Ruland and Miaskowski (2009), in a literature review of 192 articles conducted in Norway, found that family caregivers carry a great burden whilst taking care of the terminally ill family member. It is not only the nursing or physical responsibilities that are difficult, but also the additional responsibilities, such as extra household tasks that are time consuming for the family members. Transporting and emotionally supporting the patient and extra errands was not as difficult as performing nursing tasks such as washing and clothing the patient (Stenberg et al., 2009). Considering the additional burden that family members need to carry it does not seem unreasonable that they feared the unknown future.

Shotton and Seedhouse (1998) explain that an individual has dignity when he or she is in a situation where they can apply his/her capabilities. Although the patient participants did not use the term dignity, it could be argued that by fearing loss of dependence, expressed as "*I don't want to be totally dependent or so sick that I can't take care of myself*," they feared they might lose their dignity. Chochinov, Hack, McClement, Kristjanson and Harlos (2002) found that functional capacity, referring to the patient`s ability to perform daily tasks for himself and symptom distress affects the patient`s dignity as there is a relationship between symptom distress and a sense of dignity. As evident by "*You stay nauseous all the time, you don't have any strength, and you can`t do anything*" symptom distress was robbing patients of their dignity.

It is unclear whether it was the fear of death, or the fear of the unknown future, or a combination of the two that resulted in some patients thinking about euthanasia. In addition, it was interesting to find that only patient participants raised this issue. According to Seale and Addington-Hall (1994), patients have thoughts of euthanasia because they anticipate the end stage of their disease, severe suffering and a very poor quality of life. Johansen, Halen, Kaas, Loge and Materstvedt (2005) agree with Seale and Addington-Hall and add that fear of future pain and a painful death are the main reasons for wishing for euthanasia. Breitbart, Rosenfeld, Pessim, Kaim, Funesti-esch, Galietta, Nelson and Brescia (2000) found that depression and hopelessness are the main predictors for wishes for a hastened death. However, Johansen et al. (2005) found that wishes for

euthanasia were future orientated, changeable and undecided and dependent on the precondition that hopelessness, intense pain and a poor quality of life would be present.

When reflecting on the chemotherapy they received, patients felt that although they were informed about the expected side effects, they were still unprepared when side effects occurred. Fortunately, as supported by "*it was better than I thought it would be*," some patients did not experience the side effects as anticipated however, some were not so privileged.

Pain was a major problem – not only for the patients but also for the families. As supported by a family member's statement "*the pain is so uncomfortable that I don't know what to do*," family members felt helpless when they were confronted with the sick person's pain. In addition, as supported by "*it never stops paining here*," patients experienced chronic unmanaged pain. This does not seem to be the exception. Sykes and Thorne, as cited by Reynolds, Drew and Dunwoody (2013) in 2003, found that 51% of end of life patients have pain. Although slightly less, Smith et al. in 2010, found 46% of end of life patients had pain in the last month of their lives. Van der Beuken-van Engerdingen, de Rijke, Kessels, Schouten, van Kleef and Patijn (2007), when reviewing 52 studies on pain over the last 40 years, found 64% of patients who were in an advanced, metastatic or terminal phase had pain and that one third of those patients reported their pain to be moderate to severe.

Experiencing pain has various consequences as Van Dorrepaal, Aaronson and van Dam (1989), in a study investigating the experience of cancer pain, found that patients experiencing pain showed a decrease in daily activity and higher levels of sleep disorders. It was also found that patients with chronic pain later developed anxiety, nervousness and depression. Whether the patients in the current study experienced these consequences of pain is not clear as this was not specifically explored and therefore a conclusion cannot be made.

As supported by "*it never stops paining here*" it might be quite reasonable to conclude that pain caused suffering. Baines and Norlander (2000: 319) found that pain and suffering are related as pain causes suffering, but suffering can occur without pain. The authors also found that an increase in pain leads to an increase in suffering, not only in the physical domain but also to spiritual suffering, loss of enjoyment in life, concern for loved ones, unfinished business and fear of the future. As evident from the current study, it was not only pain and physical symptoms that caused suffering. This poses a serious challenge to palliative care practitioners taking over the care of patients after palliative chemotherapy and their families, to limit suffering by preventing and relieving pain and other symptoms.

The pain the patients experienced made the family members feel helpless as they were not able to ease their pain as evident by "*it sometimes feels as if nothing helps*" and "*I wish I can take the pain away*." As cited by Milberg, Strang and Jakobsson (2003), Rupert found that powerlessness or helplessness is one of the biggest psychological factors related to the caretaking experience. In addition, the helplessness found in the current study is supported by Milberg et al. (2003), who states that the experience of helplessness is related to the patient`s pain and the feeling of not being able to control the current situation. Wong and Chan (2007) also found that family members experienced helplessness but changed when they accepted their relative was going to die and then hoped they would have a peaceful death. Helplessness has far reaching implications for the family and Milberg et al. (2003) found these experiences can have a negative impact on the health of the family member taking care of the terminally ill patient. Helplessness has physical and psychological symptoms such as anxiety, sleeplessness and depression, with family members also feeling lonely and isolated and fearing loneliness in the coming future. To support the consequences of the helplessness the family members in the current study experienced would not be possible, as this phenomenon was not explored. However, the researcher believes these effects might also be part of the lives of the families in the current study as they found themselves in the same life situation as the families researched.

Pain was not the only symptom the patients were burdened with; they reported nausea, vomiting, constipation, fatigue and anorexia, as seen by *"I mean it`s the nausea, I can't eat."* Given, Given and Kozachik (2001) support this finding by stating that in conjunction with the progression of the disease, the patient has a progression of symptoms such as nausea, anorexia, fatigue, shortness of breath and they tend to be more dependent on their caretakers. In addition, Vainio and Auvinen (1996), in a study conducted in Finland, found that besides pain, weakness, anorexia, constipation and nausea were the symptoms most reported. Rhodes and McDaniel (2001) found the symptom experience varies as the disease progresses, with advance disease patients having a more severe symptom burden. In addition, nausea, vomiting and retching are complex problems in palliative care, with patients suffering from nausea and dyspnoea experiencing more pain than patients not burdened with these symptoms.

It was interesting to find some patient participants were relieved the chemotherapy was stopped, whilst others were devastated. As evident by a patient stating "*it was like being totally deserted"* and a family member saying "*we have been written off*" both the patients and families felt they were failed and abandoned. This is not unique as Back, Young, McCown, Engelberg, Vig, Reinke, Weinrich, McGrath and Curtis (2009), in a study

conducted in the US, found the same trend as the patients and families in their study felt abandoned and were of the opinion they no longer have access to medical expertise. They felt their doctor was no longer involved in caring for the patient and they were left to their own devices, with only Hospice to seek medical advice from. The participants felt that near to death someone else took over their care and they lost continuity of the relationship they had developed with their physician.

Some patients resorted to alternative therapies in the hope that something could still be done for their cancer. This is not unique as Molassiotis, Fernandez-Ortega, Pud, Ozden, Scott, Panteli, Margulies, Browall, Magri, Selvelcerova, Milovics, Bruyns, Gudmunsdottir, Hummerston, Ahmad, Platin, Keoney and Patiraki (2004), in a study conducted in 14 European countries, found that irrespective of what health care practitioners may think of alternative treatment and even when they are dismissive about these practices, patients use and will continue to use alternative therapies. It is not clear how the patients in the current study selected the alternative therapies as this was not explored, but the authors discovered they make use of a wide variety of sources of information, the biggest source being word of mouth from family and friends. Unfortunately using alternative therapies could be problematic as not all the treatments work for everyone, even if they have the same symptoms. As to whether these kinds of treatment are “good” or “bad” for patients who are terminally ill is debatable; what is of concern are the expectations these therapies might create and not live up to, which could add to the losses the patients and family members are confronted with.

It was interesting to find the patient participants did not mention financial constraints, whilst this seemed to be of great concern for some families as evident by: *“I did a cash transfer to one of the hospices. I mean they went to get authorisation for home nursing*” and “*I don’t know if the doctor can prescribe it in such a way that the costs can go through the medical aid*”. Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, Willan, Viola, Coristine, Janz and Glossop (2004), in a study conducted in Ontario, found that a caregiver`s economic burden increases in conjunction with the illness of the patient progressing. They also found that prescription drugs were one of the biggest expenses that contributed to the economic burden and that the burden is even heavier when there is no access to medical insurance. In a study conducted in Florida, Haley (2003) found the time devoted to taking care of elderly cancer patients could have been spent being paid for working and also the average time of caretaking is about ten hours a week. He also found all extra medical expenses need to be paid by the patient and/or the family (Haley, 2003).

Coping and accepting their impending death was not easy. As evident by *"on the road ahead things will get worse*" some patients knew it was going to get more difficult, while others hoped they wouldn't suffer too much as evident by "*I have a feeling that I won`t suffer too much.*" In addition, as supported by *"I don't want to think about it,*" some family members did not want to think about the impending death of the patient. Higginson and Constantini (2008) found that patients living with advanced cancer have complex emotional reactions knowing that they are in end of life. They are worried about their family and finances, they have spiritual needs and have feelings of anger, guilt and fear of their impending death whilst being burdened with unrelieved symptoms. McCormick and Conley (1995) found that when patients learn death is inevitable they experience many fears; they fear pain, loss of independence and finally loss of self. Thompson, Chochinov, Wilson, McPherson, Chary, O`Shea, Kuhl, Fainsinger, Gagnon and Macmillan (2009) noted that patients who had access to open communication with their family found it easier to discuss their fears with them and therefore had better acceptance of their impending death. In addition, as cited by Thompson et al. (2009), Prigerson (1992) noted that when a dying patient`s caretaker accepted the patient`s death it was easier for the patient to accept it.

As evident by "*He will take care of me*" and "*trust God*" religion played an important role in the lives of both the patients and family members. This finding is supported by Balboni, Vanderwerker, Block, Paulk, Lathan, Peteet and Prigerson (2007), who state religion is very important to most advanced cancer patients. In addition, it was found the more religious the patients were the more open they were to extreme measures of treatment to prolong life. With the thought that their fate was in "*higher hands*" patients hoped for the miracle of cure, as also seen in the current study. Tarakeshwar, Vanderwerker, Paulk, Pearce, Kasl and Prigerson (2006) found that religious coping is a very important aspect of a patient`s quality of life whilst McClain, Rosenfeld and Breitbart (2003) found that spiritual well-being can provide some protection against end of life despair when death is imminent.

When applying the Navigating the Unknown Waters theory to the findings, it became evident that all the processes described in this theory came to the fore whilst interviewing the participants. The interaction between these processes is what eventually brings the patient and the family to a point where they have transitioned from a palliative patient with anti-cancer treatment to a palliative patient without anti-cancer treatment. Transition took place in four areas of the participants' lives. These areas are environment, physical and mental health, roles and relationships and lastly daily activity changes. Their environment

changed, as evident by "*they won't allow me to go home once more,*" patients were moved from their known environment to a different one where they could be taken care of. Even if they stayed in their known environment, things changed to accommodate their needs of being a person with advanced cancer. Their physical and mental health changed as supported by "*she gets impatient…her memory is fading*." In addition, roles and relationships changed, not only did the family become the caretaker of the patient, but also the patient lost the relationship they had had with staff at the cancer care setting where they received treatment expressed as "*you build a relationship with that person, and yes, you don't see that person again, you know… it`s just goodbye and they give you a hug*..." Lastly participants experienced transition in their normal daily activities, described as "*I can hardly get in and out of bed*. *I can hardly get into the bath.*" These transitions could only take place with the on-going interaction of three sub processes which, in conjunction with the interactions, are described next.

The sub process of coming to terms with was seen in the study in terms of the following three steps: to acknowledge what happened, connecting and redefining normal. The sub process of coming to terms with was seen in: "*I don't know how far the cancer will go, but I must live with it and accept it*" which meant the patient was aware of the terminal phase he had reached and accepted it. Next they have to compare their life to where they are now: "*my husband and I worked so hard for it, you know it is beautiful furniture that I have and I just want to go home once more and get to divide and give away my things*." In this step the patient reminisced about their life and compared it to the phase they were now in, which was seen more often in older patients. The last step was to reframe their hope and set new goals for themselves, goals they thought would achievable in this terminal phase: "*At first the pain medication did not help, but they increased the strength and now it helps and I made peace, because I can now walk around again and I am not lying in bed all day and I can do things for myself.*" It was important to be able to do things for themselves again and to achieve that goal.

The next sub-process was the process of connecting, which included three steps. The first was to actively seek information usually by asking questions of the doctor or searching for information online. The next step was to search for options as illustrated by "*I drove to hospice to find out what they have available and to find out where they are*" and the last step was to connect with trusted experts as supported by "*if it wasn't for the visits from the Hospice sister, then I don't know what we would have done.*"

The last sub-process has two steps, one was to redefine normal and the other was to be able to define when to worry. This meant the patient and family needed to set new

standards of ‘well’ for the patient in the terminal phase. ‘Normal’ could simply be to be pain free and comfortable, as seen in: *“we want her to be comfortable and we are content with that.*” When the family and the patient established what was ‘normal’ for them in that terminal phase, they were able to define when disease complications were above their normal range and they had to seek advice.

All these sub processes were facilitated by three factors; timely communication, information and support. The patients did not mention whether they thought the information they received was in good timing or adequate. However, as supported by “*I get a lot of help from people. People come here and ask what they can do for us and his kids. CANSA helps a lot* ” patients and family members agreed on the importance of support.

4.6 SUMMARY

In Chapter Four the findings of the study was discussed in view of the available literature. In Chapter Five, the justification, limitations and recommendation for further research will be discussed.

CHAPTER 5

JUSTIFICATIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter will justify the study in terms of research purpose. The intention is to conclude and evaluate the study in terms of positive contribution to the body of scientific knowledge and to discuss the limitations. Finally, recommendations will be presented for nursing practice and research.

5.2 JUSTIFICATION OF THE STUDY

The study will be justified in terms of its purpose, which was to explore how patients treated at a private cancer care setting in the Southern Cape region of South Africa and their families experienced the transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment.

The research methods and design were described in detail in Chapter 3. Chapter 4 presented the findings of both the patient and family participants and discussed the findings. The study is therefore justified because the purpose of the study was achieved.

5.3 LIMITATIONS OF THE STUDY

The study had various limitations. This was a qualitative study with a small sample determined by data saturation. The sample size is not representative of the South African population and therefore the results cannot be generalised to the larger population. The study was conducted at one private cancer care setting in the Southern Cape using a convenience sample method. This means the results of the study cannot be generalised to other private cancer care settings serving palliation patients in other areas and can also not be generalised to patients being cared for at public health cancer care settings. In addition, no qualitative study presents the only true meaning, as there could be more than one interpretation of the narratives. However, the researcher believes the themes originating from the data were authentic and might be applicable to other patients and

family members transitioning from palliative care with anti-cancer treatment to palliative care without such treatment, as there could be overlapping issues which might apply to other patients and family members.

5.4 RECOMMENDATIONS

Nurses practicing in cancer care settings should perform a needs assessment to determine the needs of the patient and family during transition from palliation with anti-cancer treatment to palliation without anti-cancer treatment. This would enable nurses to render individualised patient and family care based on their specific needs. In addition, nurses should investigate a system where a primary nurse, for each patient receiving palliative chemotherapy, is identified and tasked to continue the care of the patient and family after palliative chemotherapy has been stopped. This might prevent patients and families from feeling failed and abandoned by the health care team who had cared for them when they received anti-cancer treatment.

Lastly the researcher recommends that this study is followed up with an intervention study, testing nursing interventions to ease the transition of patients and families to palliative care without anti-cancer treatment members when palliative chemotherapy is no longer feasible.

5.5 CONCLUSION

Transitioning from palliation with anti-cancer treatment to palliation without anti-cancer treatment was a traumatic experience for both the patients and their families, which added to their suffering. When learning nothing more could be done, patients and family participants experienced shock. Being confronted with death made patient participants feel scared and for some, euthanasia seemed to be an option whilst others hoped for a cure with alternative therapies. Some family members were able to accept the impending death of the patient, whilst others did not want to think of what was lying ahead. Both the family and the patient`s felt sad and some, even abandoned by the health care team responsible for the palliative chemotherapy, whilst others were happy to be referred to a palliative care team. While carrying the burden of terminal illness, some patients and families were supported by other family members, friends, the church and CANSA, whilst others had no support. Patients did not want to lose the ability to take care of themselves.

Participants had to deal with symptom burden, with pain being the most debilitating of all. Family participants felt distressed and helpless whilst having to care for the terminally ill patient, during which time having to witness the deterioration of their loved one. To add to their emotional distress they also had to deal with the financial implications of taking care of a terminally ill patient. Some patient participants accepted their impending death whilst others denied the fact they were terminally ill. Patient participants feared both the future and that they were going to suffer at their end of life. Religion gave some patients and families comfort and hope, while others maintained hope they would be cured.

5.5 REFLECTION ON EXPERIENCE

When planning this study, I was under the impression there would be many patients and families who would be able to participate in the study. Only after commencing the interviews did I realise that patients receive anti-cancer treatment until they are too sick or weak to return to the cancer care setting where I practice. Recruiting participants for the study was a challenge and I could not help but become anxious at times.

I became aware of what patients experience when they leave the cancer care setting as a palliation patient without anti-cancer treatment. They have to deal with feelings of shock, abandonment, sadness, fear and hope. I also learned patients feel that we, the doctors and nurses practicing out-patient cancer care settings, fail and abandon them when they reach the end of palliative chemotherapy road and are referred to “pure” palliative care providers. The fact that they lose regular contact with us added to the many losses they experienced. This saddened me and I started wondering how we can extend care to prevent this dire situation.

As an oncology nurse practicing in an outpatient cancer care setting, I never realised what patients and their families experience when at home. As one family member mentioned, nurses tell them about the expected side effects and they listen, but when it actually happens they feel alone and scared and don’t know what to do. Hope is what makes them get through the day, with the love and support of family and friends and for some, their religion.

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ADDENDUM A

INFORMATION LEAFLET AND INFORMED CONSENT FOR PATIENT

THE TRANSITION FROM PALLIATION WITH ANTI-CANCER TREATMENT TO PALLIATION WITHOUT ANTI-CANCER TREATMENT: A PATIENT AND FAMILY EXPERIENCE

Goodday

My name is Maretha Combrinck and I am currently a student at the Department of Nursing Education at the University of the Witwatersrand and as you know also practicing as registered nurse at this cancer care setting. I would like to invite you to take part in a study that I am conducting at this care setting. 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, Maretha Combrinck at (044) 8840806 during office hours. You should only agree to take part if you are completely satisfied with all the procedures involved.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of the study is to explore how you as the patient treated at this private cancer care setting and their families experience the transition from being a patient receiving anti-cancer treatment to a patient without anti-cancer treatment.

WHAT WILL YOU NEED TO DO IN THE STUDY?

If you would like to take part in the study, you will need to sign a consent form. This will allow me to interview you and to use the information that you give me to write a scientific report. I would invite you to tell me about yourself and to tell me of your experience while transitioning from a palliative patient with anti cancer therapy to a patient without any anti-cancer therapy or being a family member of such a patient. After this initial interview that would take about an hour of your time, I will ask your permission to interview you again on a day and time that would be convenient for you.

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

Only patients who received anti-cancer palliative treatment at this private cancer care setting and have moved to palliative care without cancer treatment and their families can take part in this study. You also have to be at least 18 years old.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

Due to the nature of this study you might experience emotional discomfort when sharing your experience with me. For me to find out what you have experienced may unfortunately cause emotional discomfort. If you are experiencing emotional discomfort I will request the counsellor practicing at this cancer care setting to see you. This is a service that is provided to the patients and their family members free of charge. This would only be done with your permission. Please remember that you may decide at any time during the interview that you don't want to participate in the study any longer. You are perfectly within your rights if you do decide to withdraw and your decision will not influence the treatment and care that you of your family member are currently receiving.

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

By participating in this study you will help us to understand the experience of a patient when they transition from a palliative patient with anti-cancer treatment to a palliative patient without anti-cancer treatment and their families. If we have better insight in the experience of the patient and the family, it would help us to find ways to improve the care and support to the patient and his family during the transition. There are no benefits for you personally and you will not be paid for your participation.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

It is your decision to participate in the study. It is your right to withdraw from the study at any time, even during the interview. You have the right to decide that I can't use the information you gave during the interview. However, after all the interviews have been transcribed the names of the participants will be removed and I will not be able to know which information belongs to you. This means that I would not be able to withdraw your information any more.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED FOR THE STUDY?

What you say to us is strictly confidential and only my supervisor and I 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 transcribe the interview I will remove your name and your name will not be used when I write the report.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Before inviting you to take part in the study, the Human Research Ethics Committee of the University of the Witwatersrand and the Ethics Committee of this private cancer care

setting 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 Prof Peter Cleaton-Jones on 011-7172100.

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

Yours sincerely,

Maretha Combrinck (Registered Oncology Nurse) Tel: 044 8840806

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 _____

ADDENDUM A[1]

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, ... have consented to be a participant in the study being conducted by Maretha Combrinck 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 ☐

Participant's signature or mark.....

Investigator's signature.....

ADDENDUM B

INFORMATION LEAFLET AND INFORMED CONSENT FOR FAMILY MEMBER

THE TRANSITION FROM PALLIATION WITH ANTI-CANCER TREATMENT TO PALLIATION WITHOUT ANTI-CANCER TREATMENT: A PATIENT AND FAMILY EXPERIENCE

Goodday

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Only patients who received anti-cancer palliative treatment at this private cancer care setting and have moved to palliative care without cancer treatment and their families can take part in this study. You also have to be at least 18 years old.

WHAT ARE THE RISKS INVOLVED IN THIS STUDY?

Due to the nature of this study you might experience emotional discomfort when sharing your experience with me. For me to find out what you have experienced may unfortunately cause emotional discomfort. If you are experiencing emotional discomfort I will request the counsellor practicing at this cancer care setting to see you. This is a service that is provided to the patients and their family members free of charge. This would only be done with your permission. Please remember that you may decide at any time during the interview that you don't want to participate in the study any longer. You are perfectly within your rights if you do decide to withdraw and your decision will not influence the treatment and care that you of your family member are currently receiving.

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

By participating in this study you will help us to understand the experience of a patient when they transition from a palliative patient with anti-cancer treatment to a palliative patient without anti-cancer treatment and their families. If we have better insight in the experience of the patient and the family, it would help us to find ways to improve the care and support to the patient and his family during the transition. There are no benefits for you personally and you will not be paid for your participation.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

It is your decision to participate in the study. It is your right to withdraw from the study at any time, even during the interview. You have the right to decide that I can't use the information you gave during the interview. However, after all the interviews have been transcribed the names of the participants will be removed and I will not be able to know which information belongs to you. This means that I would not be able to withdraw your information any more.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED FOR THE STUDY?

What you say to us is strictly confidential and only my supervisor and I 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 transcribe the interview I will remove your name and your name will not be used when I write the report.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

Before inviting you to take part in the study, the Human Research Ethics Committee of the University of the Witwatersrand and the Ethics Committee of this private cancer care setting 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 Prof Peter Cleaton-Jones on 011-7172100.

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

Yours sincerely,

Maretha Combrinck (Registered Oncology Nurse) Tel: 044 8840806

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 _____

ADDENDUM B1

CONSENT FOR AUDIO-TAPING OF THE INTERVIEW

I, ... have consented to be a participant in the study being conducted by Maretha Combrinck 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 ☐

Participant's signature or mark.....

Investigator's signature.....

ADDENDUM C

Nursing Education

INTERVIEW SCHEDULE (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=

Section B

- Please tell me what you experienced from the time when learning that anti-cancer treatment cannot be continued until now?
- Was palliative treatment discussed with you by doctor and what do you understand palliative medicines to be?
- What are your feelings regarding this change in focus regarding your treatment?
- What are your expectations during this terminal phase?
- Knowing all further treatment will aim at symptom management how will this have an impact on your life?
- Do your loved ones understand the implications of this decision?

INTERVIEW SCHEDULE (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	Q5=
	Up to grade 7	2	
	Grade 8 – 10	3	
	Grade 11 – 12	4	
	Tertiary	5	
Relationship to patient	…….		Q6=

Section B

- Please tell me what you experienced when learning that _____ anti-cancer treatment cannot be continued until now?
- Was palliative treatment discussed with you by doctor and what do you understand palliative medicines to be?
- What are your feelings regarding this change in focus regarding your family member`s treatment?
- What are your expectations during this terminal phase?
- Knowing all further treatment will aim at symptom management how will this have an impact on your life?
- Does your loved one understand the implications of this decision? What support are you receiving?

ADDENDUM D

DATA ANALYSIS PROTOCOL

Tesch in Creswell (1994) has provided the following steps to when transcribing unstructured 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 "participant" 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.

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

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms MJW Combrinck

CLEARANCE CERTIFICATE	**M120602**
PROJECT	The Transition from Palliation with Anti-Cancer Treatment to Palliation Wthout Anti-Cancer Treatment: A Patient and Family Experience
INVESTIGATORS	Ms MJW Combrinck.
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 24/08/2012 **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...

gvi oncology
Committed to excellence in Cancer Care

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24/07/2012

University of the Witwatersrand, Johannesburg
Department of Nursing Education
Human Research Ethics Committee (Medical)

R.E.: R14/49; M120602; Ms. MJW Combrinck

To whom it may concern

Herewith official permission for Ms. MJW Combrinck to perform her research project in our unit, the Outeniqua Oncology Unit – a member of GVI Oncology.

Please do not hesitate to contact me with any queries.

Thank you,

Ruan van Aswegen
Unit Business Manager, Outeniqua Oncology Unit, GVI Oncology
3 Gloucester Avenue, George, 6530
P.O. Box 10365. George, 6529
Tel: 044 884 0806
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t/a Dr L Gouws & Partners Inc. – PR No. 040 000 0127620 – Reg Nr 1999/025637/21
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