THE EXPERIENCES OF PRIMARY CAREGIVERS OF CANCER PATIENTS ADMITTED TO A HOSPICE

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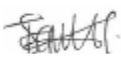
DECLARATION

I Tinalipi Sophinah Ketlogetswe, declare that the study on **"THE EXPERIENCES OF PRIMARY CAREGIVERS OF CANCER PATIENTS ADMITTED TO A HOSPICE"** is my work. It is being submitted for the Degree of Masters in nursing sciences (Oncology and palliative Care) at the University of Witwatersrand, Johannesburg. It has not been submitted before for any examination or any university.

Signature: 

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DEDICATION

I dedicate this study to God Almighty for keeping me well and giving me strength throughout the study period. Your word is a lamp at feet.

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ABSTRACT

Design and Methods A qualitative descriptive design was used for this study and conducted 22 in-depth interviews purposively selected. Sample size was determined by data saturation and qualitative content analysis was used to analyse the data. The inclusion criteria were 18 years and older, ability to speak basic English, identified by the patient as the primary caregiver and willingness to participate.

Findings: Participants had different relationships with the sick person; however, caring for a sick mother was the most common. Three themes arose from the data: emotional responses towards the care giver role, personal cost of care giving and spiritual issues relating to care giving. Caring for a person with cancer in the last phase of life was not easy. Participants were overwhelmed by the care responsibilities. Some could not cope with the new role as they were emotionally distressed. Participants were financial burdened by the care needs of the patients; care giving was costly while others sacrificed their source of income to provide care. Most participants used religious practices to cope with their situation.

Conclusion: Caring for cancer patients at the last phase of life was not an easy task. Participants were overwhelmed by the responsibilities and demands of caregiving. Most participants were emotionally exhausted and drained and feeling inadequate to perform these responsibilities. The financial burden was related to the care needs of the sick person. The caring role lead to some participants losing their jobs to provide care to their sick loved one.

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CHAPTER 1

OVERVIEW FOR THE STUDY

1.1 INTRODUCTION

Cancer is a generic term for a large group of diseases characterised by the abnormal growth of cells that can then invade adjoining parts of the body and/or spread to other organs. Cancer can affect almost any part of the body (World Health Organization, 2016, Momna, 2010). Cancer is a public health problem worldwide and it is estimated that in 2012, 14.1 million people were newly diagnosed whilst 8.2 million people died of this group of diseases (Centre for Disease Control, 2016). It is also estimated that more than 70% of the world's cancer deaths occur in low income countries, which include Africa, Asia and Central America (Cancer Association of South Africa, 2011, LeSeure and Chongkham-ang, 2015). According to the World Health Organization (2016), cancer causes more deaths than coronary heart disease and strokes. Due to the growth and aging of the population, risk factors such as smoking, physical inactivity, overweight and reproductive pattern changes associated with economic development and urbanisation, the number of people diagnosed with cancer has increased (Torre et al., 2015). According to Ferlay et al. (2015), lung, breast, liver and colorectal are the cancers commonly diagnosed worldwide.

In South Africa, cancer affects one in four of the population and each year more than 100 000 people are diagnosed with cancer, 60% of whom will survive (Cancer Association of South Africa, 2011). Lingwood et al. (2008), cited in Maree et al. (2017a), stated that most of South Africa's cancer patients present with end stage disease when cure can no longer be achieved. South African men are mostly affected by the following cancers: lung, oesophagus, colon and bladder cancers, while the most prevalent cancers amongst women are cervical, colorectal and oesophageal cancers.

According to the World Health Organization (2017), the main objectives in cancer treatment are to cure or to attain a considerable prolongation of the patients' lives and ensure the best quality of life possible for the patient and their families. Cancer treatment does not only come as a single therapy, some patients may receive a combination of therapies which include surgery, radiotherapy, chemotherapy, immunotherapy and hormone therapy (Gates and Fink, 2008,

Yarbro, 2018). Cancer patients are primarily treated on an outpatient basis due to the system changes in healthcare delivery focusing on outpatient treatment and short hospital stay. This means family caregivers became the primary source of support of cancer patients and have to cope at home, often without guidance or help from the healthcare system (Stenberg et al., 2014b, Glajchen, 2003). Linderholm and Friedrichsen (2010) and Teno et al. (2013) support this statement and add that more than half of cancer patients' end-of-life care is done by caregivers at home, or at end-of-life care units where they undertake and coordinate the majority of care. Although families often seek help for end-of -life care at institutions such as hospices, the overall care of the patient still lies with the primary caregiver. Beard (2012) described a caregiver as a family member or friend who is giving regular ongoing assistance to a cancer patient at end-of- life, doing things the patient was unable to do independently.

1.2 PROBLEM STATEMENT

The problem addressed by this study pertains to the experiences of caregivers of cancer patients who are admitted to hospices. Caregivers are not exempted from the shock, pain and suffering cancer imposes on the patient (Ghebreyesus, 2017, McIlfatrick et al., 2006). Studies that Girgis et al. (2012) conducted in developed countries have shown that the effect of being diagnosed with cancer is greater on the primary caregivers than the cancer patients. Family caregivers take on significant and unfamiliar roles when the cancer patient is being cared for at home (LeSeure and Chongkham-ang, 2015). In addition, McIlfatrick et al. (2006) and Githaiga (2017) state that caregivers share the cancer experiences with the patient and that less is known about their own experiences in the care giving journey. Maree and Schmollgruber (2014) and Maree and colleagues (2017a), in studies describing the cancer nursing research output in South Africa and Africa, found that studies primarily focus on knowledge, attitudes and practices towards cervical and breast cancer and that there is a dearth of information about the caregiver of patients living and dying from cancer, amongst others. According to Selman et al. (2018), studies on caregivers of cancer patients were conducted in the United States and Europe. To address this deficit an international evidence base is required to guide clinicians and be used as baseline data for countries lacking this kind of research. The current study will provide baseline data to address this knowledge gap in part and give appropriate recommendations based on the findings.

1.3 RESEARCH QUESTION AND PURPOSE OF THE STUDY

To address the research problem the following research question was formulated: What are the experiences of primary caregivers of cancer patients admitted to a hospice?

The purpose of the study was to describe the experiences of primary caregivers caring for cancer patients admitted to a hospice.

1.4 SIGNIFICANCE OF THE STUDY

The significance of the study relates to the knowledge gap pertaining to the experiences of people caring for cancer patients. Although this phenomenon has been researched extensively in the developed world, the same trend does not apply to Africa (Maree et al., 2017b). This study described the experiences of primary caregivers of cancer patients admitted to a hospice. Knowledge of these experiences will enable nurses to develop interventions, which can support them in their care giving journey.

1.5. SETTING, RESEARCH DESIGN AND METHODS

The setting for this study was a hospice in Johannesburg. A qualitative descriptive design (Colorafi and Evans, 2016) was used. All primary caregivers of cancer patients admitted to the hospice formed the population for this study. The inclusion criteria were: primary caregiver identified by the sick person and 18 years and older. Purposive sampling, the sampling method of choice for descriptive qualitative work (Sandelowski (2000), was used to select the sample and sample size was determined by data saturation (n=22). In-depth interviews were used to gather the data, which offered the researcher the opportunity to capture rich, descriptive data about the participants' experiences (Trotter, 2012). One question *"Please tell me what it is like for you to take care for a very sick cancer patient?"* was asked, where after probes and prompting questions were asked for participants to clarify issues and expand further on their experiences. Participation was voluntary and a digital voice recorder was used to record the interviews with permission from the participants; demographic information (Appendix D) was obtained before the interviews commenced. Qualitative content analysis Sandelowski (2010), using an inductive approach (Elo and Kyngäs, 2008), was used to analyse data. The study

adapted Lincoln and Guba's four evaluative criteria for trustworthiness guided by Shenton (2004) and Anney (2014) to enhance the rigour of the study.

1.6 CONCEPT CLARIFICATION

End-of-life (EOL): End-of-life refers to the final phase of life for cancer patients when a terminal condition has become advanced and incurable (American Cancer Society, 2017, Oliver et al., 2014).

End-of-life care: End-of-life care is broadly defined as the care of all cancer patients, especially with a terminal illness that is advanced, incurable and progressed and not only in the final hours or days of their lives incurable (Oliver et al., 2014)

Primary caregiver: For the purpose of this study, a primary caregiver is a relative, partner, friend or neighbour who assists the sick person with different health needs and daily activities of living by doing things the patient can no longer do independently (Beard, 2012, Wolff and Roter, 2010).

Hospice: For the purpose of this study, hospice will refer to a place offering specialised and unique care for patients with a life-limiting illness, together with their families and their primary caregivers (Washington et al., 2017).

Hospice care: Hospice care is a philosophy of care that focuses and attends to the spirituality, emotional, physical and social needs of the patient. It also focuses on helping the patient's family and primary caregivers cope with the disease progression of their loved ones and bereavement. Hospice care specialises in providing care in the home, and hospice services aim at allowing patients to remain in their homes for end-of-life care for as long as possible for (Casarett et al., 2015).

1.7 SUMMARY

Chapter 1 presented the overview for the study. The introduction, research question and problem statement have been presented. In addition, overviews of the research design and methods have been presented. The study will be presented as follows:

Chapter 1: Overview of the study

Chapter 2: Literature review

Chapter 3: Research design and methods

Chapter 4: Findings and discussion

Chapter 5: Limitation, recommendations and conclusion

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 1 provided an overview for the study. Chapter 2 will describe the relevant literature. Cancer as a global health problem will be described followed by cancer diagnosis, grading and treatment, palliative care and hospice care. Caregivers will also be described in this chapter.

2.2 CANCER AS A GLOBAL HEALTH PROBLEM

Cancer is a global health problem and remains one of the top leading causes of illness and death worldwide. According to the latest Globocan statistics Globocan (2012) there were an estimated 14.1 million new cancer patients and 8.2 million deaths resulting from cancer worldwide in 2012. Cancer is one of the major killers throughout the developed and developing world and has the greatest economic impact in the form of premature death and disability (American Cancer Society, 2017). According to Ferlay et al. (2015), the World Cancer Research Fund ranked South Africa number 50 in the their list of cancer affected countries.

According to the South African Cancer Association CANSA (2016), over 100 000 people in South Africa are diagnosed with cancer each year. Men have a higher lifetime cancer risk, as one in eight men and one in nine women are affected by cancer. In addition, one in four South Africans will be affected by cancer – either through a personal diagnosis or by having a friend or family member diagnosed with this disease - with breast, cervix, prostate, unknown primary, Kaposi sarcoma, lung and colon/rectum cancers being the most common. Cancer is a progressive disease and approximately 40% of South African cancer patients will not survive and enter the phase where cure is no longer possible. Whether this percentage of survivors is just is debatable as most cancer patients seek medical help for the first time when the disease is already advanced, when cure is no longer possible, which impacts negatively on their survival (Maree et al., 2017a). In addition, Kaur and Mohanti (2011) stated that nearly 50% of newly diagnosed cancer patients would die within one year after they had been diagnosed.

Cancer also carries an economic burden; treatment is extensive, costly and less successful. The financial costs of cancer are high both for the patient, family, society and the nation at large

(Pulse, 2016), however it has other quantifiable costs, such as time spent by caregivers, transportation and assistance in the home.

2.3 CANCER DIAGNOSIS, GRADING AND STAGING

An early diagnosis of cancer is essential to reduce suffering and increase chances of cure (Snyman, 2013). Various tests can be used to diagnose cancer, such as through clinical symptoms detected by means of a physical examination, diagnostic test such as blood tests, x rays, Magnetic Resonance Imaging, Computer Tomography (CT), and Positron Emission Tomography scans. However, a histopathological examination is critical for confirming the diagnosis and to guide the treatment and management of the patients (World Health Organization, 2017).

The grading of the tumour is part of the histopathological examination. Ferri (2016) explains grading as the assessment of the degree of malignancy of tumours by comparing the cellular anaplasia, differentiation and mitotic activity of the cells. Two grading systems are commonly used, one describing the cells in terms of their differentiation and one using numerical grades. The grading system that describes the cells considers low grade cancer cells as well differentiated and the tumour grows at a slower rate, whereas high grade cancer cells are poorly differentiated, fast growing and the patient is a high risk of metastasis. The numerically grade system rates cancer cells from 1 to 4 where 1 represents most differentiated cells with 4 being the least well differentiated (Ferri, 2016).

In addition to grading, patients are also staged to determine how far an individual's cancer has grown based on the size of the primary tumour and the extent of spread in the body. Diagnostic tests, such as X-rays and CT scans, are used to determine the stage of the disease. The Tumour, Node, Metastasis (TNM) staging system is one of the most common staging systems used and it classifies cancer by tumour size (T), lymph nodes involvement (N) and metastasis (M), if any (National Cancer Institute, 2015). Once the TNM staging has been determined, it is combined to determine the stage of the disease. The majority of cancers are divided into four stages, Stages I to IV, with Stage 1 being the least disease and Stage 4 disseminated disease. Some cancers have a Stage 0 (zero), which refers to cancer in situ (Yarbro et al., 2010).

In addition to the TNM staging system, prognostic indicators, such as tumour markers and tumour genetics, may be used to help determine the prognosis of the patient and decide on the best available treatment. Tumour markers are substances found in the blood, urine or body tissues of people with cancer at higher than normal levels. Genes found in cancer may be used to determine cancer treatment and patients' possible responses (Pulse, 2016).

Cancer treatment requires careful consideration of evidence-based options. Various modalities, which include surgery, radiotherapy, chemotherapy, immunotherapy and hormonal treatment, are used to treat patients with cancer. The choice of treatment depends on the location, grade of the tumour and the stage of the disease, as well the patient's performance status (Itano et al., 2015a). Performance status measures patients' general well-being and ability to perform activities of daily living and determines their ability to tolerate therapies such as chemotherapy, radiotherapy and others. The Eastern Cooperative Oncology Group (ECOG), also called the WHO score (Young et al., 2015), is the most commonly used scoring system. Muzio (2017) and Itano et al. (2015a) describe the ECOG performance status, from grade 0 to 4, as follows:

- Grade 0: patient is fully active in all pre-disease activities with no restrictions.
- Grade 1: physically restricted in strenuous activities but ambulant and can perform work of lighter nature.
- Grade 2: ambulant and able to perform of self-care but not able to carry out any work activities, up and about more than 50% of waking hours
- Grade 3: patient's performance only limited to self-care activities, spends more than 50% of working hours in bed or chair
- Grade 4: patient is not able to perform any self-care activities, completely disabled and confined to bed.

As already mentioned, various treatment modalities are used for patients suffering from cancer, including surgery, chemotherapy and radiotherapy. Surgery is local treatment and is the primary treatment in cancer. Surgery can also be used for diagnosis and staging, prevention, reconstruction and rehabilitation and palliation, as well as neoadjuvant or adjuvant treatment (Crane and Selanders, 2017).

Chemotherapy is defined as a systemic type of cancer treatment that uses cytotoxic drugs to cause damage to cancer cells (Fernando and Jones, 2015). Chemotherapy is not specific to cancer cells only as it targets all rapidly growing cells however, cancer cells are unable to repair the deoxyribonucleic acid damage, whereas normal cells can. Due to lack of specificity, chemotherapy has the potential of harming healthy tissues, especially those tissues that have a high replacement rate, for example-cells in the mouth and those in the intestinal lining; these cells usually repair themselves after chemotherapy. Chemotherapy drugs may be used as a single agent or as combination therapy with two or more cytotoxic agents where drugs enhance each other's action to prevent chances of resistance. Similar to surgery, chemotherapy can also be used as primary treatment and as an adjuvant and neoadjuvant treatment (Shaikh et al., 2017, Melamed et al., 2016). Chemotherapy is primarily administered via the intravenous route but can also be administered orally (Newton et al., 2009, Newton et al., 2016).

Radiotherapy, which can be given as adjuvant and neoadjuvant treatment (Gates and Fink, 2008, Newton et al., 2016), is a localised treatment that uses ionising material to kill cancer cells and shrink tumours by damaging the cells genetic makeup making it impossible for them to continue growing and dividing. The main aim of radiotherapy, which can be administered as external beam radiotherapy and as brachytherapy, is to kill as much cancer cells as possible while limiting harm to nearby healthy cells. To achieve this aim, fractionation is used, allowing recovery of healthy tissues between fractions. The effects of therapy are localised and confined to the treatment region. Palliative radiotherapy is given to relieve symptoms such as pain, bleeding, obstruction and others when cure is no longer possible

Hormonal treatment is a form of systemic therapy, which is non cytotoxic and prescribed for cancer patients with cancers that are influenced by hormones, such as oestrogen and testosterone (Maunglay et al., 2011). Hormonal therapy is used as adjuvant therapy to help reduce the risk of recurrence as well as neoadjuvant. Patients with locally advanced disease or metastatic disease respond well to hormonal therapy (Abraham and Staffurth, 2016).

Other kinds of cancer treatment include immunotherapy and targeted therapy. In immunotherapy, certain parts of the person's immune system are used to fight cancer. The immune system is stimulated to enhance its activities in attacking cancer cells or the patient may be given some immune system components such as man-made immune system

proteins (Borghaei et al., 2009, National Cancer Institute, 2017). Targeted therapy specifically targets the changes that are specific to cancer cells that help in growth, division and spread of cancer cells. This therapy targets specific genes or proteins that are found in cancer cells or in cells related to cancer growth, such as blood vessel cells (Newton et al., 2016).

Irrespective of the treatment used, the goal of treatment is curing the disease, prolonging cancer patients' lives and ensuring the best possible quality of life for cancer patients (Newton et al., 2016).

2.4.1 Response to treatment

The effect of cancer treatment on cancer cells is measured in terms of response. The same imaging tests used to diagnose cancer are used to monitor response. Tumour size, performance status and lymph node involvement are used in determining patients' response to treatment (Yarbro, 2018). The World Health Organization (2017), advocates that all cancer patients must be evaluated for treatment, even if treatment protocols were not followed, to determine continuity of treatment, benefits of treatment and determine the need for further testing. Response to cancer treatment is indicated as follows:

- Complete Response (CR): All targeted lesions disappear.
- Partial Response (PR): The sum of the targeted lesion's longest diameter decrease by 30% and takes the baseline sum longest diameter as reference
- There is a 30% decrease in the sum of the longest diameter of target lesions.
- Stable Disease (SD): There is no definite shrinking which can define partial response. It uses the smallest diameter sum as the reference since beginning of treatment.
- Progressive Disease (PD): Target lesion longest diameter increase by 20% or more. The smallest sum longest diameter recorded since treatment resumed or appearance of new lesions is used as the reference (Wolchok et al., 2009).

2.5 CARING FOR THE PATIENT WITH CANCER

2.5.1 Palliative care

The World Health Organization (2017) 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. Yarbro (2018) and Nemati et al. (2017) agree with this definition, but with emphases on symptoms management and spiritual and psychosocial issues of both the patient, the caregiver and family as a whole. Palliative care is aimed at improving the quality of life for the patient and family, and is a continuum of care that includes hospice care, bereavement and counselling. According to the Hospice Palliative Care Association of South Africa (2017), palliative care addresses patient and family needs, such as counselling and bereavement, through team approach. Palliative care is effective when started early in the course of illness, together with therapies such as chemotherapy or radiotherapy aimed at prolonging life. It also includes performing of investigations, which are needed to understand and manage clinical complications. Itano et al. (2015a) also emphasise that palliative care processes should be implemented as soon as a life-threatening illness has been diagnosed, but becomes the focus of care when cure or life-prolonging therapies are no longer effective.

Palliative care, as defined earlier, assists with decision making and improves the quality of care and reduces the unnecessary use of medical and technological cancer services (Temel et al., 2010). Traditionally, palliative care was always delivered late to those hospitalised in specialised inpatients, or as a consultative service for those patients faced with uncontrolled symptoms. Previously, studies had suggested that referring patients for palliative care services just before death was insufficient to change the quality and delivery of services given to cancer patients (Caraceni et al., 2012). Palliative care must be must be provided earlier during the course of disease and as soon as metastatic diseases are diagnosed so that meaningful effects on patients' quality of life and end-of-life care can be achieved (Temel et al., 2010).

Providing palliative care to South Africa's cancer patients faces the same challenges as preventing and treating cancer and similarly, those needing palliative care do not have access to such care. In many African countries, drugs needed for effective management of pain and other symptoms are not available (Maree et al., 2017a). In addition, legislations in many countries still restrict opioid prescription to medical practitioners, which cannot be afforded considering the current cancer burden and non-facility-based healthcare. Palliative care is relatively new in South Africa and has been implemented in the end-of-life phase only in the

South African context, and as such, professionals implementing palliative care principles early in a patient's illness, regardless of whether they are receiving treatment for cure or not (Temel et al., 2010).

As stated earlier, palliative care includes hospice care and other components, such as end-of-life care. Smith et al. (2012) acknowledge end-of-life care as the provision of palliative and supportive care in response to the needs of the patient, family and caregivers, as per needs assessment, during the last phase of life. Caring and offering support to patients and their families at the end-of-life is a core part of nursing care. End-of-life care operates under the palliative care concept in offering support system to help the family cope during the patient's illness and in the bereavement phase. End-of-life care builds on the following pathways: assessment and discussions as the end-of-life approaches, planning of care and review, coordination for individual patients and families, delivery of highest possible quality services in different settings, care in the last days of life of both the patient and family and care of caregivers after death (Ghebreyesus, 2017, European Society for Medical Oncology, 2017).

Although end-of-life has been regarded as a normal process, Gill and Duffy (2010) affirm that it is the most difficult phase for family members and caregivers. Smith et al. (2012) advocate for caregivers support to help them find ways of keeping things normal during the phase and that trusting relationships should be established by health practitioners. According to the National Cancer Institute of the United States (2016), end-of-life care does not intends to hasten nor postpone death. As distressing symptoms are being managed, health practitioners and caregivers should ensure that their actions do not hasten nor postpone death in end-of-life care. The term 'euthanasia' and 'assisted dying' are often used in association with managing distressing symptoms and this has caused confusion about what actions must be taken and how these actions should not end life instead of managing symptoms and comfort (Sulmasy and Mueller, 2017). Euthanasia is 'killing' on request, and a health practitioner, with prescription rights, can voluntarily, consciously and competently 'kill' the person or patient by administering drugs at the person's request. Both the health practitioner and the person should be mentally sound on making this decision. Physician-assisted suicide is defined as a health practitioner with prescription rights intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request and both parties should be mentally sound to make the decision (Materstvedt et al., 2008, Sulmasy and Mueller, 2017). It is

often thought that giving morphine to cancer patients at end-of-life affects breathing, but at this phase of life, morphine is primarily prescribed as an analgesic and in small quantities in the form of liquids to help with breathlessness; morphine doses should however be monitored and patients should be monitored for toxicity (Howard and Chady, 2012).

When caring for a cancer patient at home, in a hospice or busy hospital, it is important for families and caregivers to be given sufficient information and support as possible. Data collected from the patient and families in their initial contact are important and could be used to support the family and caregivers and to help patients live as actively as possible until death. Both the family and the patient need to understand how to manage symptoms after being given clear and concise information (Howard and Chady, 2012). Often nurses and other health personnel are busy and create no time for counselling, information sharing and support. Howard and Chady (2012) emphasise helping the caregivers and family members to deal with the situation until bereavement stage.

2.5.2 Hospice care

Hospice care as a philosophy emphasises the "good death." It originated in London in the mid-20th century (National Hospice and Palliative Care Organisation of the United Kingdom 2016). It also focuses on the following factors, which are mandatory on end-of-life care: alleviating suffering in all forms**,** effective pain and symptom physical management, treating the "whole patient" and end-of-life goals. Hospice care does not only attend to physical ailments but it also nurtures a person's emotional, spiritual and mental needs. Similarly, as in palliative care, this is also achieved through the hospice interdisciplinary team (Harborlight, 2016).

According to the Highway Hospice in Durban (Hospice Highway, 2016), hospice is both a philosophy and a programme of care that is designed to improve the quality of life for persons with a life threatening illness**.** It is further described as a group of caring people forming a community who have a shared commitment and are dedicated to promoting the spiritual, physical and emotional wellbeing of the terminally ill and their families. Hospice care provides a palliative care programme, which is the total care of patients whose disease can no longer respond to curative treatment, who experiences pain and other physical symptoms and social, psychological and spiritual challenges.

Hospice care is part of the palliative care continuum of care which focuses on the last phase of life to provide high quality care for families to live as fully as possible when cure is not possible (Itano et al., 2015a). As a continuum of palliative care, it provides care, comfort and support to patients and families who have been affected by a life-limiting illness. Hospice care is a model of quality for end-of- life care based on the understanding that dying, just like life, is part of the normal life cycle (Howard and Chady, 2012). In hospice care, patients are supported through the dying process while families are supported through the dying and the bereavement. It advocates that cancer patients live the remainder of their lives with dignity and die in a manner that is meaningful to them (Kutner and Kilbourn, 2009). Hospice care is holistic, it expands the traditional model not only to address end-stage disease but also provide other dimensions of the patient's and family's dying experience (National Hospice and Palliative Care Organisation of the United Kingdom 2016).

2.6 CAREGIVERS

A caregiver is anyone who provides assistance and care to anyone who needs it, especially those who can no longer do it independently. The caregiver is not usually paid for doing so, and the care is more profound in the end-of-life phase when a patient can only do little or nothing for himself (Ferrell and Coyle, 2006, Beard, 2012). Care giving means helping a loved one with daily needs and this may include taking the patient for doctor visits, preparing meals and feeding the patient, picking up medicines and ensuring that treatment is taken according to the plan. It can also mean helping the cancer patient cope with feelings, as it actually means being there for the patient.

The healthcare system has shifted from longer to shorter hospital stays and outpatient treatment Stenberg et al. (2014a) to reduce the economic burden of care and this has affected South Africa, as 82% of the population do not have medical aid (Stats.South Africa, 2017). Due to this shift, most cancer patients are cared for at home McIlfatrick et al. (2006) and caregivers find themselves playing the role with little knowledge and without support and guidance from the healthcare system (LeSeure and Chongkham-ang, 2015, Glajchen, 2003). LeSeure and Chongkham-ang (2015) further state that although the care giving role starts at diagnosis of cancer, the burden of care on caregivers worsens at end-of-life care when the patient is no

longer able to assume any responsibility for themselves. The impact of a cancer diagnosis affects the complete family system, leaves no one untouched especially the primary caregivers. This impact causes deterioration of quality of life for some caregivers and family members, whereas for some it increases their resilience and helps them thrive (Waldrop et al., 2015).

Caregivers have always been and remain the extension of the professional workforce for cancer and play a critical and important role in palliative care and its components of care, and studies show there is no end to a caregiver's day. The demands of care in end-of-life have shown to be more demanding than other phases of living with of cancer, when treatment plans change and when functional abilities and cognitive capabilities diminish (Given et al., 2012, Maree et al., 2017b). Caring for a cancer patient is demanding and challenging. Care giving for cancer patients at end-of-life's uniqueness and complexity varies and it solely depends on the presenting symptoms (LeSeure and Chongkham-ang, 2015). Caregivers share the experiences of cancer with the patient and little is known about their experiences in the journey of caring for the patient until end-of-life (Girgis et al., 2012, American Cancer Society, 2017).

Caregiving can be translated to a dynamic and ongoing process, which may bring about positive and negative effects. Some researchers in the oncology field stress the importance of examining caregiver experiences in relation to the phase of illness the patient is going through (Stenberg et al., 2012). Blum and Sherman (2010), cited in Maree et al. (2017b), state that caregiving influences caregivers' mental and physical health leading to anxiety, anger, depression and stress-related diseases. While giving care, they often neglect their needs and put feelings aside. In addition, due to the demands of care giving, caregivers find themselves in financial hardships and not being able to attend to any other important issue that pertains to their lives (Fenn et al., 2014).

Studies have shown that involvement of caregivers and family before death reduces the use of unnecessary technology and increases the use of comfort care as patients die (Nissen et al., 2016). They are frequently the first and last to take care of their loved ones. The ethical view holds that if healthcare personnel do well for the patient, they have also done well for the family. Families often make decisions for their loves ones when they are no longer capable and as such, they have to live with the consequences of their decisions after the patient's death in a much deeper and personal way than the palliative care team involved (Wolff and Roter, 2010). Support for family and care givers is a core function of palliative care. The caregiver's role is

important in the patient's care; it is crucial to have good, reliable support system for the emotional and physical well-being of persons with cancer.

Caregivers are involved in many activities of patient care throughout all phases of the cancer care trajectory. These activities include medication administration, symptom management especially pain management, wound care, hygiene and assistance with meals and nutritional support, emotional support, monitoring of treatments adherence, running of errands such as bill payments, as well as accessing health system resources. Other activities include coordinating care, monitoring use of electronic devices (for those needing oxygen at home) and communication with healthcare providers (LeSeure and Chongkham-ang, 2015). To provide this care, primary caregivers must have a number of complex skills and be able to make conscious and sound care decisions on behalf of patients. Despite the heavy level of care involvement of primary caregivers, it is seldom that the healthcare system assesses the unmet needs of primary caregivers as a part of patient care (Given et al., 2012, Nemati et al., 2017).

Studies have shown that a cancer patient's caregiver is a critical member of the palliative care team and therefore it is crucial to examine certain care giving factors, such as communication patient-caregiver expectations and their experiences, which might influence both patients' and caregivers' quality of life (Wittenberg et al., 2017). Working with primary caregivers is an opportunity for oncology nurses and other healthcare providers to engage in family-centred care by tailoring and adapting to their communication methods and having an understanding of their needs and expectations (Rezende et al., 2017, Pattison et al., 2013). Family has been described as a significant factor in a patient's choice of palliative care and patients tend to place greater importance on communication related to end-of-life care within their family than with healthcare professionals (Wallace, 2015). This makes it paramount for health professionals to understand how caregivers and families handle and view care giving so that appropriate interventions can be established for them.

2.6.1 Caregiver role changes and transitions

Transitions are ongoing processes in which an individual experiences change or new circumstances incorporated into their day-to-day lives. Being new to care giving often brings and causes unexpected and sad feelings. Transitions are usual sudden in occurrence and traumatic to both patients with advanced cancer and their families (Duggleby et al., 2010). Cancer

patients do not only experience physical changes in their disease trajectory but also in their mental health. They lose their ability to think clearly, and thus reduce their capability to look after themselves and change their daily life activities and those of their family members and primary caregivers (Martín et al., 2016). In this study context, multiple transitions occur in the areas of environment, physical and mental health, activities of daily living, and roles and relationships.

Patients receiving palliative care often experience multiple changes in their lives and care, such as change in treatment, symptoms, functional status and quality of life. The transitions can be confusing and traumatic to both patients with advance disease and caregivers. Some transitions result not only from the disease but also from anxiety, distress and uncertainty about how the family will handle the situation and the anticipated death in end-of-life (Mosher et al., 2013).

A cancer diagnosis does not only affect the patient but also family members, friends and significant others (Cancer Net, 2016). In every transition of the journey, caregivers are forced to make decisions which are serious and sometimes with irrevocable consequences (Lee et al., 2016). Family and caregivers of cancer patients experience multiple transitions, such as a change in roles, having to move from their place of comfort to the patient's to quit jobs to provide care to a family member and changes in their quality of life. Cancer and it's treatment cause lifestyle changes, complex and overwhelming feelings for the patients as well as the caregivers. It is important to understand the potential changes in the specific family members and friends who may want to foster health and mutual supportive relationships during the challenging time of disease projection (Magilvy and Congdon, 2000, Gozalo et al., 2011).

Transition from curative treatment to palliation and to end-of-life has been regarded as traumatic to both the care recipient and caregivers, which adds to their high levels of suffering and anxiety. When patients and family learn that not much can be done they experience shock, which consequently influences their decision making, care to their loved one and family relationship (Teno et al., 2013). In general, families face persistent challenges for which they must be organised and prepared for in order to experience a healthier transition to the new role of care-giving. It therefore important for caregivers to work closely with health practitioners, especially palliative care nurses, to ensure their needs are met and also maintain the best level of health and well-being and similarly ensure the continuity of care given to the individual patient (Ferrell et al., 2014)

Families go through some transitions because of a cancer diagnosis in the family. At the time of diagnosis, a few patients are in good health. For some patients the transition begins at

supportive and palliative care and within a short period of time they are in the terminal phase where hospice, supportive and end-of-life care is initiated (Teno et al., 2013). As transitions occur in the lives of cancer patients, the same occurs in the caregivers' lives, as their routines have to change to meet the care needs of the cancer patient. Figure 1 illustrates the transitions.

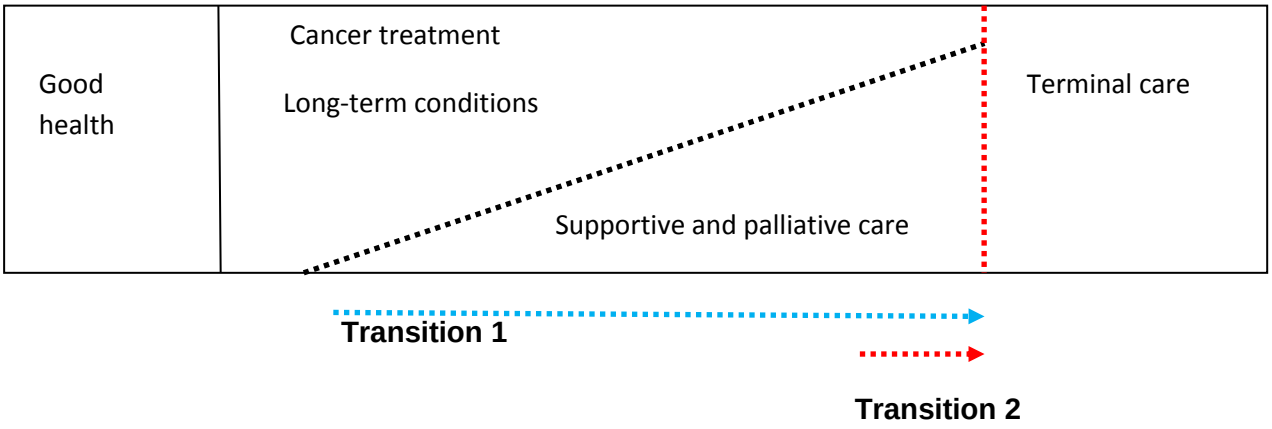

Figure 1: The transition from cancer diagnosis to terminal illness.

Itano et al. (2015b)

2.7 SUMMARY

Chapter 2 presented a literature review of the concepts of the study. Cancer as a global problem, cancer diagnosis, cancer treatment, palliative care and caregivers were also a focus of this chapter. Chapter 3 will present the research design and methods of the study.

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

In Chapter 2, literature review of the study was presented. This chapter describes the research design, the setting, sampling process, and data gathering methods and analysis procedure, ethical principles of the study as well as measures applied to ensure trustworthiness of the study.

3.2 RESEARCH DESIGN

A research design guides the planning and implementation of a study in a way to achieve accurate results. The research design is a set of logical steps, which the researcher takes in order to provide answers to the research questions (Grove et al., 2012). The study used a qualitative descriptive design. According to Colorafi and Evans (2016), a qualitative descriptive design provides factual responses to questions about how people feel about a particular topic of study. Qualitative descriptive studies aim at making comprehensive summaries of events in the everyday terms of those events. It is the most applicable method if the researcher desires straight descriptions of phenomena (Sandelowski, 2000). Although qualitative description may have different interpretations it has a low-inference interpretation, which is likely to cause easier consensus among researchers and what to be described entirely relies on the researcher (Sandelowski, 2010, Sandelowski, 2000). In qualitative description, researchers stay close to their data, facts are presented in everyday language because it is the vehicle of communication and not just a structure of interpretation that must be read. In addition, qualitative description does not commit to pre-existing theories and philosophies. Qualitative enquiry supports the views of naturalistic enquiry, which is devoted to studying a phenomenon in its natural state without any pre-selected variables, manipulation of variables and commitment to any theoretical view deducted from previous experience (Sandelowski, 2000). This design was selected for this study because the researcher wished to provide an accurate summary of how caregivers experience caring for cancer patients.

3.3 RESEARCH METHODS

Research methods include the study setting, target population, sample and sampling methods, procedures of data gathering data and ways of analysing data. Research methods are techniques that the researcher uses to structure a study and answer the research question. It is a combination of sampling and data collection, analysis and techniques of presentation (Polit, 2012).

3.3.1 Research setting

Research setting refers to the specific place where research data are collected (Brink, 2015). The study was conducted at a hospice in Johannesburg, which is easily accessible to all patients and families of the Gauteng Province. The hospice is a non-governmental and non-profitable institution, which entirely depends on donations. It has been operating for over 26 years with a bed occupancy of 12, which has not changed since its inception. The hospice admits patients in their last phase of life from greater Johannesburg, with referrals from local hospitals and community centres and those caregivers who needs respite care, and is well equipped to manage symptoms experienced by cancer patients.

At the hospice is a multidisciplinary team consisting of the manager, who is also the administrator, registered nurses, a medical doctor, a social worker and lay caregivers, who have completed a six months course on palliative care. The hospice also has registered spiritual leaders who are called in when patients' needs for spiritual support arises. On average, 25 patients are admitted monthly with a maximum admission period of 14 days. Caregivers and family members are allowed to visit their patients any time during the day until 8pm to allow patients to rest at night. Only one caregiver is allowed to sleep with the patient at the hospice. The hospice provides a home care service caring for patients at home as per patients and caregivers' requests.

3.3.2 Population

Population is the totality of all participants that conform to a set of specifications, which is the entire group of people that are of interest to the researcher and to whom the research results

can be generalised (Liamputton, 2013). The population for this study was all primary caregivers of cancer patients admitted to the hospice. To be included in the study, caregivers had to be 18 years and older, identified by the patients as the primary caregivers, caring for a cancer patient who was 18 years and older and able to understand basic English. The participants were caregivers of adult patients (patients 18 years and older) and having cared for the patient for hours to days.

3.3.3 Sampling, sample size and recruitment

The process of sampling selects a portion of the population that represents the entire population to make inferences about the population (Cleary et al., 2014, Sandelowski, 2010). Polit (2012) describes a sample as a portion or a subset of the research population selected to participate in a study. Purposive sampling, the sampling method of choice for descriptive qualitative work (Sandelowski, 2000), was used to select the sample. In this sampling method, only participants who would be of most benefit to the study were consciously selected. The sample size was determined by data saturation (n=22). Liamputton (2013) and Grove et al. (2012) agree that data saturation refers to the point where new categories, themes or explanations stop emerging from the data and when enough rich, meaningful data have been obtained to achieve the study aims.

Recruitment of participants involves two major tasks: identifying eligible candidates and inviting them to participate (Polit, 2012). The researcher recruited primary caregivers as they visited their sick family members at the hospice. The researcher was practicing as a nursing student in the field of oncology and palliative care at the hospice. Eligible candidates were approached and verbally invited to participate in the study. In the case of patients being unable to speak, the professional nurse identified the primary caregiver as per the history taken at admission. The study was explained to the caregivers recruited and informed consent was obtained from them before the study. Twenty-four (24) caregivers were recruited and 22 volunteered to participate, while two were not ready to be interviewed.

3.4 DATA GATHERING

Data gathering is an organised and structured gathering of information relevant to the research purpose (Cleary et al., 2014, Gill et al., 2008). In-depth interviews were used to gather the data. In-depth interviews offer the researcher the opportunity to get hold of rich, descriptive data about peoples' experiences (Trotter, 2012). In-depth interviews also help the researcher develop an understanding of the logic behind participants' responses as they are a one-on-one conversation between the researcher and the participant (Krystyn, 2016). One opening question: '*Please tell me what it is like for you to take care of a very sick cancer patient?'* was asked, where after probes and prompting questions followed to encourage participants to clarify issues and explain further and expand on their experiences as needed (Polit, 2012). The first interview served as pre-test to determine whether the question posed was easy to understand. No problems were experienced and the interview formed part of the data analysed. The researcher, who gathered the data, was a female registered nurse studying for a Master's Degree in Oncology and Palliative Care Nursing, and had been allocated to the hospice three months prior to conducting the research for work-integrated learning.

The planning for the data gathering was as follows:

- After obtaining the necessary permissions from the university and hospice, the staff members in the hospice were informed of the study and their support was obtained. The researcher intended not to cause any disruption to the daily functions of the hospice.
- The patients were approached to identify their primary caregivers. In instances where the patient could not communicate, the professional nurses assisted in identifying the primary caregiver.
- Caregivers meeting the inclusion criteria were approached by the researcher and invited to participate in the study. The researcher explained the study and obtained the informed consent.
- Data were gathered over a period of four months between August and November 2017.
- Interviews were arranged at a time convenient to the participants and conducted at the hospice in a private room, which was designated for counselling sessions.
- On average, interviews lasted for 40 minutes.

3.5 DATA ANALYSIS

Data gathering in qualitative studies occurs simultaneously with data analysis**.** Qualitative content analysis, the preferred analysis method for qualitative descriptive work, according to Schreier (2012) and Sandelowski (2000), was used to analyse the data. Qualitative content analysis is defined as a research method where the content of text data is subjectively interpreted through a classification process of coding and identifying themes. This type of analysis classifies large amounts of text into a manageable number of categories representing a similar meaning (Schreier, 2012). In qualitative content analysis, data are presented in words and themes, which allow the researcher to draw some interpretations of the results. An inductive approach (Elo et al., 2014) was used. When using an inductive approach, the text is analysed with an open mind in order to identify meaningful subjects to provide answers to the research question (Bengtsson, 2016).The data were analysed as follows:

- The interviews were transcribed word for word.
- The transcripts were read and re-read and notes and headings made in the margins. This process was repeated to make sure the headings describing all the aspects of the content were written down.
- The headings were transferred to coding sheets and categories were generated.
- The categories belonging together were grouped as sub-themes. The sub-themes were grouped as themes. Higher order headings were allocated to the themes (Elo and Kyngäs, 2008).

Three people were involved in the coding of data; the researcher and one of the supervisors coded the data, which was confirmed by the second supervisor after consensus was reached. The researcher used reflexivity whilst analysing the data to be aware of their position in life and the possible influence to the study's findings. Reflexivity is a process where researchers reflect on themselves to provide a fair and impartial analysis. The researcher consciously acknowledges the preconceived thoughts and assumptions they bring into the research and therefore shape the outcome (Anna, 2015).

3.6 ENHANCING RIGOUR

To enhance the rigour of the study, the researcher applied the four trustworthiness criteria defined by Lincoln and Guba, as summarised by Shenton (2004): credibility, transferability, dependability and confirmability.

3.6.1 Credibility

Credibility refers to the degree to which the findings reflect the actual experiences of the participants and a reflection of how believable the results are. It is also the confidence that can be placed in the truth of the research findings (Milne and Oberle, 2005, Anney, 2014). Credibility was enhanced in the following ways:

The researcher used well-known research methods, confirmed through peer review, which also enhanced the credibility of the findings. In addition, the researcher developed an early familiarity with the study setting as she was allocated to the hospice before data gathering and so was familiar with the procedures and culture of the study setting. A relationship of trust was also established with the institution and the participants before each interview. Participation was voluntary and only caregivers who volunteered to take part in the study were included, thus enhancing honesty. Participants were also allowed to tell their own stories in their own way. Probes were used to promote richness rather than superficiality of data. Questions asked during the interviews were rephrased to ensure accuracy of information given. The researcher also used member check during the interviews to enhance credibility. On the spot member checking was done; the interview was also summarised at the end. The researcher practiced in a cancer care setting two months before gathering the data and was a student in a specialist course in oncology and palliative care nursing at the time of data gathering. The credentials of the researcher enhanced credibility.

3.6.2 Transferability

Transferability, also known as applicability, refers to the degree to which qualitative research results can be generalised or transferred to other contexts or settings (Elo et al., 2014, Shenton, 2004). In ensuring sufficient data were collected during each interview, the researcher enhanced rigour of transferability through thick descriptions. Purposive sampling was used; participants were purposely selected considering their knowledge and experiences of studied research topic. When additional participants provide no new information and themes become

repetitive, data is considered rich and thick (Gigi, 2017). The researcher provided sufficient information about the research setting to allow the reader to make a transfer (Shenton, 2004). In addition the necessary information about recruitment, data gathering and analysis methods were described in the study proposal and the report.

3.6 3 Dependability

In addressing dependability, techniques must show that repeating the same work in the same or similar context, with the same participants and same methods, the researcher would obtain similar results (Shenton, 2004). To enhance dependability, the research design, and how it would be used in the study, was reported.

3.6.4 Confirmability

According to Leung (2015), confirmability refers to the degree or extent to which the results of the study could be validated or verified by others. The participants in this study represented different genders, language and cultural groups, and cared for patients with a variety of cancer diagnosis. The researcher enhanced confirmability through an audit trail and data triangulation. The viewpoints and experiences of individual participants were verified against others and ultimately, a rich picture of the experiences, needs or behaviour of those under study was constructed based on the contributions of a range of participants. As Shenton (2004) emphasises triangulation in confirmability, different methods were employed during data gathering. Individual interviews were done, notes taken as necessary and the observations were made as participants shared their experiences.

3.7 ETHICAL CONSIDERATIONS

The Health Professional's Council of South Africa's guidelines (2017) for Health Researchers were followed to conduct ethical, acceptable research. The following principles were adhered to, to protect the rights of participants:

Autonomy and consent: The participants were free to choose whether they would like to be involved in the study. Participants were also made aware that participation was voluntary and

that withdrawing from the study would not pose any risk for them. Prior to obtaining the participant's consent, the researcher provided comprehensive and clear information regarding their participation in the study. An information leaflet was also handed to them (Appendix A) for further reading.

Possibility of harm: This principle encompasses freedom from harm and exploitation (Brink, 2015). No harm was intended however, due to the sensitive nature of the study emotional discomfort could have been experienced. A special arrangement was made with the hospice's social worker to be available in case of need for referral of participants during interviews. The social worker was given the schedule of the researcher's data gathering days. No participants were referred for emotional support as participants expressed feeling better and emotionally relieved after the interviews.

Anonymity: Pseudonyms were used and no identifiable data were disclosed during reporting of findings. Participants were also informed that the reporting would not disclose any information, which could identify them.

Confidentiality and privacy: Participants' rights to privacy and confidentiality were respected. Participants' responses will not be shared with anyone who is not part of the research team. Interviews were conducted in a private room provided by the hospice and transcribed data passwords were protected.

Respect for dignity: The principle includes the right to self-determination and to full disclosure (Graneheim and Lundman, 2014).The researcher respected the participants as persons, requested consent and acknowledged their intrinsic worth, dignity and sense of value. Without any coercion, participants independently decided to participate or not in the study. Participants' rights were respected; if any question caused discomfort, they exercised their right not to answer, and were allowed to seek clarification about any aspect that caused some uncertainty.

Justice: This principle refers to participants' right to fair selection and treatment, to be treated fairly and equitably (Amankwaa, 2016). Equity requires distributing the benefits and burdens of research participation fairly in such a way that no subset of the study population is unfairly burdened by the harms of research or denied the benefits of the knowledge generated from it (Grove et al., 2012). No person was unjustly excluded from study based on race, gender, sexual orientation, disability, religion or beliefs. The participants were not included in the study in a judgmental manner but the inclusion criteria, which stated the following was used: should be 18

years and above, be identified by the patient as the primary caregiver and having cared for the patient from hours to days.

3.8 SUMMARY

Chapter 3 described the research design and methods, the setting of the study, sampling and recruitment, how data were gathered and analysed. Chapter 4 will present and discuss the findings of the study.

CHAPTER 4

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

Chapter 3 described the research design and methods of the study, Chapter 4 present the findings and discussion.

4.2 THE PARTICIPANTS

The participants consisted of 22 primary caregivers, most of whom were female (19 of 22), aged between 23 and 84 years, with an average age of 52 years (SD ± 15) and a median of 51. The participants had cared for a sick person for between one month and 24 months, with an average of 13 months (SD ± 7.9) and a median of 13 months. Most of the participants were employed (12 of 22) and married (13 of the 22). Participants had different relationships with the sick person, however, caring for a sick mother or mother-in-law was the most common. In Table 4.1, the general characteristics of the participants are presented; pseudonyms are used.

Table 4.1 Demographic Information and Characteristics of the Participants

PARTICPANTS						CARE RECIPIENTS			
Pseudonym	**Age**	**Gender**	**Marital status**	**Cultural group**	**Employment status**	**Relation-ship to care recipient**	**Period of care (months)**	**Age**	**Reported cancer diagnosis**
Naomi	23	Female	Single	Portuguese	Student	Sister	14	26	Nasopharynx
Anita	30	Female	Single	English	Employed	Mother	11	71	Thyroid
Carol	32	Female	Single	English	Unemployed	Mother	2	62	Tongue
Nicky	37	Female	Married	Tswana	Employed	Mother	24	61	lung
Thelma	42	Female	Single	Afrikaans	Employed	Partner	12	54	Breast
Grandular	44	Male	Single	English	Employed	Mother	12	69	Ovary
Leon	44	Male	Single	English	Employed	Partner	1	48	Renal
Lerato	68	Female	Married	Tswana	Employed	Mother	24	90	Breast
Neo	45	Female	Married	Afrikaans	Employed	Son	24	19	Lung
Noodley	50	Female	Married	Afrikaans	Unemployed	Husband	10	51	Oesophagus
Antoinette	51	Female	Single	English	Unemployed	Partner	12	60	Bladder
Elaine	51	Female	Single	English	Employed	Mother Father	18 18	70 74	Sternum Sternum
Alice	52	Female	Married	Xhosa	Unemployed	Daughter	11	37	Breast
Nomsa	54	Female	Married	Sotho	Self-employed	Husband	24	67	Prostate
Emma	55	Female	Married	coloured	Retired	Neighbour	18	52	Cervix
Angelah	57	Female	Married	English	Employed	Mother-in law	6	75	Vulva
Mary	60	Female	Married	English	Employed	Daughter	12	30	Breast
Michelle	68	Female	Married	English	Employed	Mother	24	90	Breast
Kenny	69	Male	Married	Afrikaans	Pensioner	Wife	1	70	Lung
Puso	73	Female	Married	English	Pensioner	Husband	24	78	Mesothelioma
Zena	76	Female	Married	English	Pensioner	Husband	24	72	Non-Hodgkin's lymphoma
Annah	84	Female	Married	Sotho	Pensioner	Husband	24	87	Prostate

4.3 THEMES AND SUBTHEMES ARISING FROM THE DATA

Three themes and eight subthemes arose from the data. The themes are emotional responses towards the caregiver role, the personal cost of caregiving and spiritual issues relating to caregiving. The themes and subthemes are presented in Table 4.2.

Table 4.2 Themes and subthemes arising from the data

Themes	Subthemes
Emotional responses towards the caregiver role.	Feeling overwhelmed by the care responsibilities. Coping with the caregiver role. Coping with the impending death of the loved one.
The personal cost of care giving.	The physical demands of caregiving. The financial burden of caregiving. The social implications of caregiving.
Spiritual issues relating to care giving.	Conflicts between faith and reality. Faith gives strength.

4.3.1 Theme 1: Emotional responses towards the caregiver role: "I don't have a life..."

This theme discusses the following subthemes: feeling overwhelmed by the care responsibilities, coping with the caregiver role and coping with the impending death of the loved one.

Feeling overwhelmed by the care responsibilities

The participants agreed that the caregiver role came as a shock to them; however, they felt obliged to take this role. For some it was a family responsibility whilst some felt they had to return a favour. Elaine said, *"I also feel like I must do it for them because they looked after my daughter when I was very sick…"* Anita added, *"I am the only child. Not only that, I am the only one who can take care of her, it is hard…"* Some felt that the healthcare professionals had forsaken their responsibilities and "dumped" the sick person on them. They wished they could

have the life they knew before becoming the caregiver back. Naomi said, "*Health professionals should not have dumped her on me like that. As long as a person is still alive something can be done…not to be told go home and die…they could have done something… I just want a time where I can have my life back …I don't have a life…*"

The participants were overwhelmed by the caregiving role and some did not cope with what was expected from them. They described caregiving "difficult" and "terrible." The participants agreed that the caregiving role was challenging and were of the opinion they fulfilled these roles inadequately. They felt they were not doing enough to meet the needs of the sick person and were not sure if what they did helped. Some felt emotionally drained and fatigued and wanted to give up. Nicky said, *"It is a stressful and unsure process, you do not know whether you are doing the right thing or not. You don't understand the whole thing…"* Marry added*, "It is very difficult because you don't know how to attend to her needs especially when it comes to pain, nausea, vomiting and all that…"* Lerato said, "*To be honest I cannot say I have been doing a great job of caring for my father because I cannot even take care of myself now. I am concentrating on him and it feels like I am not doing enough. I am so tired and drained. Somehow I feel like giving up..."*

Participants agreed they lacked knowledge about what their caregiving roles were and the responsibilities expected from them. Most used "trial and error" in their caregiving and hoped for the best outcome. Although they were of the opinion they did everything they thought was best for the patient, they felt this was not enough. Lerato said, *"It is just a trial and error situation because at first I didn't know that I was dealing with cancer..." Puso said, "...I am concentrating on him and it feels like I am not doing enough."* Neo added, "*I never have knowledge of what I am doing. I just do things from nowhere."*

Participants also felt the support they received from the health practitioners throughout the caregiver journey was not sufficient and that their own needs were not recognised and taken care of. Naomi said*, "The hospital did not help much; they only said they cannot do anything, the patient needs home care and I didn't know what home care is…"* Leon added, *"...but as the person deteriorates it becomes hard and that is the time you need emotional support more. Unfortunately the support is not always there. The doctors and nurses worry about the patient and forget that you are also hurting as the carer or family…"*

Participants agreed the caregiving role was more difficult if the person was close to the caregiver (partner, sibling, son or daughter).They felt so emotional about it, which affected their

decision about the care, and as a result, they became impatient and intolerable. Naomi said, "*It is very difficult to care for someone, especially when you love them; it also affects your judgement*." Thelma added, *"Emotionally it is very hard when someone is very close to you."* Noodley said*, "It is probably the hardest thing if it's somebody that you love."* Lerato added*, "It is even harder and emotionally when it is someone close to you..."*

Coping with the caregiver role

The participants reacted differently to the caregiving role. Some could not cope and became emotionally distressed. For some the burden of caregiving became so hard that they wanted to abandon the sick person and run away. Naomi said, *"I called my mum and told her that she need to come here as soon as possible before I run away, I have come to point where I feel like running away… When I see her sleeping, it is fine. Once I see her crying it drives me crazy and makes me angry and I end up shouting at her … I really can't tolerate it…."* Nomsa added, *"One day I thought of running away and leaving him there. I was very scared. It was not because I wanted to leave him; I was very scared and didn't know why I was running away. I was tired of being in that situation. I didn't want to see myself in that situation and thought running away will make me feel better…"*

The participants agreed that having to care for a terminally ill person was emotionally draining and exhausting and some could not cope with this situation. Thelma said*, "…emotionally it is very hard when it is someone close to you; it takes a lot of strain emotionally*…" Leon added*, "It is emotionally exhausting because you see the person you love going through so much pain and suffering and you can't do anything about it. That is the worst thing*…" Antoinette said*, "…emotionally it is very hard, I can't deal with this. I can feel his pain and stress and this depresses me. It hurts when I see him suffering because he cannot talk and tell me how he is feeling…"*

Having to care for the sick person was not easy. Some were embarrassed with the changed person they had to care for whilst others became withdrawn. As a result, participants became social isolated, they could no longer meet with other people and they did not want visitors anymore. Kenny said, *"I feel embarrassed; people don't know her like that. I also don't know her like that... you can't believe she is the same woman. The reaction at home is an embarrassment not only to me but to other people who visit…"* Grandular said, *"I am not an emotional person; I become detached, I keep things inside. It is difficult for me to share because it is painful. I get very quiet, very withdrawn and I really don't want to talk to people about my mother. I can't keep*

peoples' company when something is eating me inside." Annah added, *"Socially I have been cut off because of the caring role. I can't meet and eat with other people anymore*."

Most participants were of the opinion that they shared the pain and distress of the sick person, a situation they were unable to cope with, and which resulted in emotional and physical distress. They described it as "I feel the same pain the patient feels…" Lerato said, *"You share every moment with him, either good or bad. So you go through the same pain the patient goes through…the pain that he feels I also feel. The pain may be different but I have emotional pain and this pain end up leading to depression and high blood and others…"* Thelma said, "…*you know when she expresses pain, it's like I also feel that pain and it hurts a lot…"* Nicky added*, "…we are spiritual very connected to each other. It feels like part of me is dying, I can feel it dying…"*

The sick person being admitted to the hospice triggered different emotions. For some, this was a relief to have the sick person cared for at the hospice as it relieved their care burden, whilst for others the hospice symbolised hopelessness. Michelle said, "*…so we brought her to the hospice and that really relieved us of the burden of caring. She is cared for properly here. That helped us a lot. We are not always worried we know she is well taken care of…"* Anita added, *"…the care she received from the hospice has really been good. I think we are so lucky. So since she came here it has been a relief for me because I don't have to worry about how I will cook for her. Hospice is a God sent place…"* In contrast, Naomi said, *"I was very afraid when she got admitted here because most of the time we do believe that when a person comes to the hospice, it means there is no more hope…I was very much afraid on the first day."*

The participants agreed that being the caregiver was not purely a negative experience, as they had some positive experiences, which enhanced coping. Spending time with the sick person and receiving support with caring was positive for them, describing these experiences as "beautiful" and "getting to know each other." Angelah said, *"I think we have bonded a lot. Even my son-in-law was helping me take her for radiotherapy so that I could go to work… we complement each other…Everybody deal with it their own way. Everybody tries to participate to help me. I wouldn't make it without my family…."* Thelma added, "*The good thing is that you get to spend more time with the person, get to know her better, pay attention to the little things that they are doing. You try and know what their needs are. We are obviously still able to talk…" Neo added, "...but it helped us to be close especially me and my husband as well as the children…"*

Participants agreed the support they received from work colleagues, friends, church members and family helped and kept them going. Leon said, *"Fortunately at work I told them my situation and they understand. They support me emotionally; they keep checking on me, I always receive calls from them. It keeps me going; at least I know that somebody cares about me."* Angelah added*, "At work I have a very good manager, he understand me having my mum sick..."* Ellaine concluded, "…*the lady who was here is also one of my friends. She has been really supportive."*

It was interesting to find some participants did not want counselling as they felt it would not make the problem disappear; others found counselling very helpful and encouraging, it helped them face life again. Some desperately needed counselling and the interviews were like a pre-counselling session to them as it helped them reflect on themselves. Zena said, "*I do have a counsellor and this has really helped. ...but at the end of the day she helps me find out ways of dealing with my situation."* Anita added, "…*I think it would be beneficial to talk to someone like a counsellor who knows about this type of situation and just guide me on how to do things. ...Maybe it will be helpful to just get some pointers on how to deal with this and how I could be better …you just help me relief some of the issues that have been eating me up."* In contrast, Marry said, "*Counselling has been recommended to me but I don't think it is going to help me. The only way I can be helped is when my daughter gets better and is cured. Other than that talking to people is not going to change the situation. I just have to accept it and bear with it..."*

Coping with the impending death of the loved one

Not all the participants were able to cope with the impending death of their loves ones, but some were able to accept it although it was not easy. Kenny said, "*Having lung cancer and it goes to the brain there is no way out…I think she is going to die…I have made peace that she is going to die… I cannot change it. I mean you have to accept what is in the plate…"* Anita added, "*Just a week ago I told my friend that I wish my mum could die, not that I don't want her, hate her or whatever, it is because it is hard. I think for her she is better on passing on so she won't have to suffer anymore."* Leon added, *"I think I am prepared but it is difficult. Reality is that he is not coming out of this place, it is just difficult to believe what you see…"*

For some, the impending death of the sick person brought fear, anxiety and the anticipated emptiness when their loved one finally died; they had uncertainties about the future without the sick person. Antoinette said, *"It is so difficult for me, I am anxious all the time. It is hard to let*

him go, I don't know how I am going to do without him…" Emma added*, "I am going to miss her so much because we used to do lot of things together, I don't know how life is going to be like without her…"*

Learning that anti-cancer treatment, even palliative treatment, is no longer feasible and that "nothing" could be done to postpone the death of the sick person, brought sadness and pain to the participants. They felt powerless and experienced this reality as "painful," "sad" and 'hurting." Neo said, *"Well, they told me that there is nothing they can do now for him, the disease is too advanced and he is now weak for an active treatmen*t." Ellaine added, *"… they told me, it was too late for any treatment for my father...I cried a lot. I was so upset and so sad…"* Kenny added, *"She was too weak at time of diagnosis and it was already stage 4. So no doctor will want to treat somebody weak like that with a strong treatment. The other doctor said chemo will kill her instantly because she is too weak, so nothing can be done."*

The participants were overwhelmed by the burden of caring for their loved ones. They reacted differently, for some it was hard and unbearable while others took it as an opportunity to bring the family members close to each other and spend more time with the sick person. It was difficult, hard and unbearable for them. Although some coped with the impending death of the sick person, it was not easy as they anticipated emptiness knowing they would have to live without the person. Some participants had some positive experiences which were related to the emotional and tangible support they received from families and friends.

The participants were shocked they had to become the caregiver but felt obliged to take on this role. Some felt that the healthcare practitioners had forsaken their role and 'dumped' the sick person on them. The participants were overwhelmed by the caregiving role, believing the care they provided was inadequate and that they could not cope with what was expected from them. The participants felt they did not receive recognition and support from the healthcare practitioners and were of the opinion they did not do enough to meet the needs of the sick person. Caregiving was emotionally draining and exhausting and some participants became emotionally distressed. However, caring for the sick person was not only negative and the support from family members' friends, colleagues and the church made the caregiving journey bearable. Some were consoled by the fact that their loved one was admitted to the hospice, as it relieved their care burden, whilst others were afraid and experienced it as situation of hopelessness. Counselling was also important to some of the participants, whilst others were of the opinion it would not help as the situation they found themselves in would not change.

4.3.2 Theme 2: The personal costs of caregiving "I am tired…"

This theme consists of the following subthemes: the physical demands of caregiving, the financial burden of caregiving and the social implications of caregiving.

The physical costs of caregiving

The participants agreed that caregiving was physically demanding and draining. The fact they had to perform the activities of daily living the patient used to do for themselves while having to perform their own daily activities drained them physically. They described the physical costs of caregiving as "tiring," "exhausting," "draining" and "demanding." Naomi said, *"I had to go to school, cook for her, feed her, and do her laundry, which was quite challenging…"* Anita said, "*I wake up very early, bath her and prepare her breakfast and feed her before I go to work. I help her with what I can before I go to work. After work the same continues…I have to sort out a few things before going to bed…"* Lerato also added, "*I have to bath my father, do his laundry and do everything else that he used to do for himself."*

Participants agreed that caregiving resulted in physical challenges, as it was a 24-hour job. Sleep deprivation was a major challenge for most of the participants, whilst some also experienced pain, migraine headaches, backache, fatigue and stress-related diseases, such as hypertension. Antoinette said*, "I am tired! I am tired. Like I said I used to have a couple of hours of sleep when he could still sleep but now I hardly sleep and my body has taken a lot of strain I can feel it..."* Anita added, *"I have been having migraines lately. I have lower back pains and my friend, who is a yoga teacher, told me that a lot of times caregivers carry stress on their lower back. It is very stressful…"* Neo said, *"I have lots of pain in my body. I can't sleep well but I am just ignoring everything so that I can focus on my son. Whatever pain I take it as nothing. Sometimes I can't sleep; I have this pain on my whole left side. There is nothing I can do about it now; I just have to concentrate on him now, he needs me. I will go to the hospital when all this is over…"*

The financial burden of caregiving

The participants experienced a heavy financial burden to provide necessities for the sick person, despite the fact that some of the patients had medical insurance. They described caring as "expensive" and "financially draining." Participants had to pay for hospital bills and

consultation fees in clinics as needed, some had to buy medication and bandages, and pay transport costs to take patients to hospitals or wherever they needed to go for healthcare. Some patients needed their diet modified, which also added to the caregiver's financial burden. Anita said, *"…financially it is a huge burden because I have to buy her some dressings, she has got a wound on her left heel that she got while she was on skin traction and it has been there since January. So I take her to the wound clinic and they prescribe dressings. Last month when we went to the clinic, we had to get a special dressing and that was R500.00… that's tough!"* Leon added, "*It is bad actually; he has not been working for two years so his medical aid is no longer active. Everything that needs to be bought for him I have to buy... so it is really bad and draining. Everything has to change including budgets. I can't buy myself anything anymore all funds have been redirected to him…"* Participants agreed that as the sick person's condition deteriorated, the cost of caring also increased. Grandular said, "*Having a terminal illness is very, very expensive and draining, every five minutes you have to try this and that, you just try to get ahead of things, you change this and this. Especially with pain you try this and this, hoping it will work…"*

Some participants lost their livelihoods, as they depended on the sick person who was the breadwinner, whilst others had to hire help to care for the sick person – something they could not maintain due to the cost. Alice said, *"It was better when she was still getting her salary, after six months they stopped her salary. Now it is so difficult, I didn't even have money for taxi to come here this morning*…" Zena explained, *"I couldn't handle it anymore and I hired a carer to assist me after he was discharged from the hospital. I was emotionally affected and finished, I needed help but after six weeks we could not afford a carer anymore…"*

Taking the role of the caregiver had a negative influence on the work life of the participants. Some were unable to continue working, whilst others lost their jobs. Carol said, *"We are very poor and now it's worse. I had to stop working to take care of her at home, no one could do it and I obviously had no money to pay a caregiver…"* Nomsa added, *"I have not been able to sew and sell clothes since his condition became worse. I earn a living through this business but now…"* Anita said, *"I lost my second job because I had taken my mother to the hospital and she was admitted that day. They fired me because I was not at work. So my finances have really taken a toll…"*

Having to care for the sick person also resulted in concentration problems, which had a negative influence on the work performance of the participant. In addition, participants feared that they

might lose their jobs due to not functioning optimally and making mistakes. Lerato said: *"My work is also affected because now I have to take care of him all the time....at work they cannot afford to have you not coming to work or making mistakes because they employed you to produce results. Even if you go to work, your mind is not there, I am not able to concentrate. It affects your performance at work. There is a risk of losing the job here…"* Anita concluded, *"So during the day when I am at work, I worry that I leave her alone and I can't concentrate well at work…"*

The social implications of caregiving

Participants agreed that caring for the sick person resulted in them neglecting the very people who were close to them and who needed their attention and love the most. Spending a "lot of your time" caring for the sick person made it hard for them to meet the needs of other family members. Lerato said, "…*now my time with my children is affected. I am not able to spend time with my children the way I am... I have to give him a priority…"* Antoinette added, *"I haven't been talking to my son but I don't want him thinking that I am ignoring him because I a focusing on my partner. I know I will catch up with him soon and everybody else..."* Anita said, *"My boyfriend says that I have become very distant. Although he understands what I am going through, it has taken a toll on my personal relationship. We no longer have time for each other and there is nothing I can do about it. She is my mother; I have to take care of her…"*

Not being able to the meet the needs of other family members caused conflicts, which added to the burden of the participants. Mary said, *"Ahh, my husband is angry and takes it out on me… I hope we will sort it out. My son is withdrawn and doesn't say much…"* Nicky added**,** "… s*ometimes they get angry because you are not there most of the time to meet all their needs. There has been some tension lately between me and my husband because he thinks I am ignoring him, but I am not…"*

The participants also agreed that being the caregiver resulted in role changes; this was especially distressing for children who had to take care of a sick parent. For some, their culture did not allow them to assist the sick person with certain activities of daily living. Angelah said, "*Right now I am squashed between my job, caring for my mother-in law, roles change, I have a year old child, I have my husband... you want to do everything for everybody but you can't…"* Lerato said*, "It is not cultural for a female child to take care of the father. Imagine, I have to bath my father and he has to be naked in front of me… it is not easy for him. It is emotionally affecting him also and that is why sometimes he gives me resistance when I try to bath him…"*

Taking care of the sick person resulted in some participants having to move home in order to fulfil their role as caregiver. The participants were of the opinion they no longer have lives and longed to have their old lives back. Leon said, *"… I work in China, I had to come back home and care for him".* Elaine added, *"When their condition changed I moved in with them, I couldn't do it from my place but that means I can no longer do things I used to do for my daughter.*"

Caregiving was physically demanding and draining. Over and above the normal care giving roles, participants had to perform roles the sick person used to perform. They experienced physical health challenges and sleep deprivation, which resulted in migraine headaches, backache, fatigue and stress. Participants also experienced a heavy financial burden and this worsened as the patient's condition deteriorated and needs increased. The caregiving role resulted in some disruption to their normal lives and changes in roles, neglecting their own family members and conflict between them and other family members.

4.3.3 Theme 3: Spiritual issues related to care giving "Why must I drink from this cup?"

This theme consists of subthemes: conflicts between faith and reality and faith give strength as the subthemes that stemmed out from the data.

Conflicts between faith and reality

Some participants experienced hopelessness and felt spiritually empty, as if God had let them down. They felt God had not answered their prayers, despite their commitment to Him, and this made them doubt and lose their faith in Him. The participants were also angry at God because they had to witness the suffering of their loved ones. Participants described their journey as a "journey without direction" and wondered why they had to face such a situation. Marry said, *"I was angry with God. I really was, because you go through life believing…they tell you that call to God when you need help but when you call and you really need help there is no help…"* Zena added, "*I was very angry at God because my husband has never enjoyed his life ...he didn't have a life that he would have loved to have. So I got angry. The spiritual feeling I had before faded away…"*

Some participants were confused by the fact that their prayers were not answered. They also felt they could not fight anymore, as what was meant to be would happen despite their prayers.

Kenny said, *"...So you speak to God but you don't know if He really listens to you. If He answered all of us this place would be a very beautiful place to live. Even those who do wrong things would also ask for His blessings and He would bless them."* Anita added, "*I am not a religious person, not that I don't believe in God. I believe what is meant to be will be…"*

Faith gives strength

Most of the participants emphasised that faith was their source of hope and strength. The participants experienced every day as unpredictable and trusted God to give them strength and hope especially when they pray. They believed that although it was hard for them, God would see them through and lighten the weight for them. Noodley said, *"It is surprising that I can still wake up and face another day and not be exhausted such that you just want to fall in a little heap and sleep? It's because only God gives me strength, only the higher power. No medication on earth can help…"* Angelah said, "*We are Christians and this helps. He encourages me to read the word, to pray, to have faith and to believe. We may not always have the right answers. God knows what is best for us. You know when you need money for bread, sometimes God just sends someone to bring you bread…"* Lerato added, *"I am a Christian and I pray when it is difficult for me…"*

Some participants used yoga as a spiritual practice, experiencing it as comforting and calming. Leon said, *"…I do yoga, it is my spiritual support. Spiritual support should come from within regardless of how your body feels. It is the spiritual part that gives the body strength."* Anita added*, "Spiritually I started yoga and this help to calm my mind a bit and gives me strength…"*

Some participants appreciated having someone to support them in prayer, although believing in God and praying became difficult during the time caring for the sick. Lerato said, *"I told my pastor so that he can pray with me because sometimes it is hard to pray for yourself because when you are in that situation all you see is a dark cloud. It is also important to have someone to support you spiritual to say God is with you and who will constantly remind you about God and He can see your situation*." Emma added, "*The Muslim ladies supported me in prayer and that really helped…"*

Participants were overwhelmed by the caregiving role and experienced it as difficult and terrible. Some could not cope with what was expected of them and became emotionally distressed, drained and exhausted. The participants were subjected to role change, which resulted in

conflict in some families. The financial burden was also significant because some participants could not cope with the demands of buying what the sick person needed and hospital bills became an issue; the burden was more significant for those families without medical aid. Over and above the financial challenges, some primary caregivers had to sacrifice their jobs or lost their jobs, which were their sources of income to provide care. However, faith and religious practices played an important role in the lives of the participants. For most participants God was their strength and they had faith in Him. They believed that even though it was hard, God would make the burden lighter for them. Participants also believed in the power of having someone supporting them in prayer, as praying could be difficult when faced with a challenge.

4.4 DISCUSSION

The study provided evidence that having to take on the caregiving role was a shocking experience. In addition, the participants could not choose whether they wanted to fulfil this task, but were obliged to care for the sick person. Some felt that the healthcare professionals had forsaken their role and 'dumped' the sick person on them, leaving them with the feeling of being unsupported and that their own needs were not recognised and taken care of. This is not unique, as Girgis et al. (2012), in a study conducted in the United States of America, found the majority of caregivers in their study reported they took on the role because it was a family responsibility and there was little choice or no other person to take the role. In addition, Maree et al. (2017c), when describing the experiences of caregivers of cancer patients admitted to hospital, found that taking on the caregiving role was not voluntary but something resulting from a cancer diagnosis. Additionally, finding that healthcare practitioners do not acknowledge or address the needs of the caregivers is not limited to caregivers of cancer patients. Gusdal et al. (2016), when describing the experiences and needs of caregivers of patients with heart failure, found that caregivers' care giving was taken for granted by healthcare practitioners and their need to be acknowledged was not met.

Caregiving was not easy and the participants were overwhelmed with what was expected from them. They lacked knowledge of how to care for the sick person and felt the care they provided did not meet the sick person's needs. Most used "trial and error" in their caregiving and hoped for the best outcome. Maree et al. (2017c) also found that the caregivers in their study were overwhelmed with what was expected of them. In addition caregivers lacked knowledge about how to provide care and made decisions about pain management with no or insufficient guidance. Kalnins (2006), when describing the experiences of Latvian family caregivers, found

that family caregivers lacked knowledge on how to provide care and made decisions about pain management with insufficient guidance. In addition, the same study described caregivers' actions as trial and error, as they performed duties for the sick person without knowing whether their actions would bring positive results. Gusdal et al. (2016), in a study conducted in the United Kingdom, also found that caregivers lacked knowledge while performing this role and ended up doing anything just to see if their actions would bring positive results.

Care giving was emotionally and physically draining and exhausting and some participants became emotionally distressed and developed physical ailments. Caregivers expressed high levels of fatigue, migraine headaches, backache and stress, which for some led to hypertension. Harding et al. (2012), in describing the perceived needs and challenges of informal caregivers in home care palliative care, found caregivers presented with similar ailments to the current study. Furthermore, Oyebode et al. (2013), on examining personal experiences of partners of individuals with motor neuron disease, found the level of fatigue increased due to the lack of sleep caregivers faced on a daily basis. This finding supports the finding of the current study, that together with physical exhaustion, participants experienced significant emotional burdens and were emotionally exhausted, which resulted in anger, sadness and fear. Martín et al. (2016), when describing experiences of family caregivers caring for a terminal patient at home, found a similar trend and explained that the emotional exhaustion of caregivers affected their quality of life, as they could no longer cope with other basic needs. Due to the physical demands and complexity of the caring role, participants neglected themselves and could no longer look after themselves as they used to before caring for the sick person. Maree et al. (2017b) also found in their study that caregivers neglected themselves due the demands of caregiving responsibilities.

Some of the participants believed they experienced the same distress their loved ones experienced, which added to their burden. Sharing the sick person's distress has been supported by Friedemann and Buckwalter (2014) in a study focusing on the family caregiver role and burden. The authors found similar results where caregivers shared the same distress and pains as the sick person. Linderholm and Friedrichsen (2010) explain this phenomenon by suggesting that the attachment between the two, leads to the caregiver experiencing the same physical or emotional distress as the sick person.

However, caring was not only a negative experience and gave the caregivers and sick person the opportunity to spend time together and renew their ties. In addition, the support from family

members, friends, colleagues and the church made the caregiving journey bearable. Various studies found the same trend, for instance Schulz and Sherwood (2008), when investigating the physical and mental health effects of family caregiving, found caregivers had positive experiences. In addition, Kalnins (2006) found that caregivers had positive experiences as they felt they had done all they could and had fulfilled the patients' wishes. The caregivers also developed new skills from the caring role, which would help them handle situations better in the future. Totman et al. (2015) found that the support network of caregivers provided a sense of security and shared responsibility. Family caregiving made the caregivers feel good about themselves and strengthened their relationships with the sick person.

As evident from the current study, having the sick person admitted to a hospice triggered positive experiences for some of the participants. Some felt it was a relief as they could have a break and reflect on their caregiving roles. In addition, the hospice also relived their burden as they didn't have to worry about the care their loved ones received. Totman et al. (2015) found that once patients were admitted to a hospice, participants reported reduced emotional exhaustion and wished hospice admissions could be longer so that they could have some time for themselves. Lambert et al. (2013) also described the positive experiences of caregivers during admission of their sick person.

Caring for a sick person had a negative influence on the work life and financial status of the participants. Some lost their jobs because of the burden of caring, some sacrificed their source of income to meet the demands of the care responsibilities, whilst others said their work was influenced as they were unable to concentrate on their job. Maree et al. (2017b) also found caregivers faced the same challenges of losing or sacrificing their jobs to meet the care demands. Totman et al. (2015) suggest that caregivers who had multiple roles, such as being employed, faced several challenges in their work place to the extent of giving up their jobs; they also had difficulty in concentrating at work, which also put their jobs at risk.

Caring for a terminally ill patient was expensive, as participants experienced a heavy financial burden in meeting the needs of the patients. Paying hospital bills, buying consumables and transportation costs added to the burden of the already overburdened participants. Brazil et al. (2012) support this finding and explain that caregivers of patients who are near the end of their lives experienced financial challenges related to patients' needs and care demands. In addition, Sopcheck (2016), when describing economic, social and political issues affecting end-of-life

care, found that as the demands of care increases due to deterioration, the costs of care increased affecting the well-being of caregivers. This same trend was found in the current study.

Becoming the caregiver influenced the relationships participants had with significant others as they neglected other people who needed them. This neglect resulted in conflicts among participants and their family members and/or partners. Similarly, Stenberg et al. (2014a), when describing the perceived burden of family caregivers of cancer patients, found that caregivers reported conflict between themselves and their family members; Penner et al. (2012) also found that the emotional burden of the caregiving role prompted conflicts between caregivers and their partners and/or close family members.

It is evident from the current study that some participants lost hope in God, as they believed He had not answered their prayers. Witnessing the pain their loved one experienced made them angry as they expected God to intervene. Some participants saw no reason to continue praying as prayer would not change their situation. Although no supporting evidence for this finding could be found, the current study provided evidence that believing in God and seeing no results deriving from prayer caused spiritual emptiness, hopelessness and anger. However, some participants used their faith and their religious practices as a coping mechanism to help them with the caregiving burden; they found comfort in praying and believing that God would help them and lighten the weight of caregiving for them. This was not surprising, as Papastavrou et al. (2012), Asiedu et al. (2014) found that caregivers trusted in God for their strength and continued praying regardless of the challenges they experienced.

4.5 SUMMARY

Chapter 4 formulated the findings of the study according to the participants' responses. Findings of the study were also discussed in view of the available literature. In Chapter 5, the justification, limitations and recommendations for further research will be discussed.

CHAPTER 5

JUSTIFICATION, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In Chapter 4, the findings of the study were presented and discussed. In this chapter the justification, limitations of the study, recommendations and a brief reflection will be presented.

5.2 JUSTIFICATION OF THE STUDY

The purpose of the study was to describe the experiences of primary caregivers of cancer patients admitted to a hospice. Chapter 1 presented an overview of the study, Chapter 2 gave the literature review, Chapter 3 described the research methods and design and Chapter 4 presented the findings and discussion in relation to available literature. The study is therefore justified in terms of the purpose, which was to describe the experiences of primary caregivers of cancer patients admitted to a hospice.

5.3 LIMITATIONS OF THE STUDY

The current study is based on in-depth interviews with primary caregivers caring for cancer patients who access healthcare in the public service. Caregivers' socioeconomic status should be considered when transferring findings to other caregivers, even those in the rest of South Africa. Although all participants were fluent in English, the fact that the interviews were only conducted in English might have led to some participants not sharing all the information they would have shared if their local languages was used.

In addition, in qualitative studies a narrative could have more than one interpretation, meaning no qualitative study presents the only true meaning. However, the researcher believes themes that originated from the data were authentic and could be applicable to other primary caregivers of cancer patients admitted to a hospice.

5.4 RECOMMENDATIONS

Nurses practising in cancer care settings, general clinics and palliative care units should assess the support and educational needs of caregivers, and develop and implement a care plan for these people.

Development of a booklet focusing on the most common problems caregivers experience is recommended to guide them on the management of the patient, and from where to get support.

Caregiver support groups could be formed to allow caregivers to share their experiences and learn positive coping mechanisms.

Lastly, the researcher recommends that this study be followed up with an intervention study to develop support programmes for caregivers at home on the care of cancer patients.

5.5 CONCLUSION

Caring for cancer patients at the last phase of life was not an easy task. Participants were overwhelmed by the responsibilities and demands of caregiving, with some participants being emotionally exhausted and drained and feeling inadequate to perform these responsibilities. Caregiving was trial and error for most of the participants, and hence were concerned that they were not proving good care. Their roles changed to accommodate the needs of the patients, and with their focus shifting to the patient, this caused family and relationship tensions and conflicts. Participants found caregiving very demanding, exhausting, overwhelming and stressful due to the physical demands they had to face caring for their loved ones; they also experienced a heavy financial burden in meeting the care needs of the patients. Participants used faith and religious practices as a coping mechanism, faith was their source of strength and kept them going despite the challenges they faced.

5.6 REFLECTION

When I first proposed the study, I visited hospices to identify an ideal setting for the study. During my visit to the chosen setting, many patients were visited by their caregivers. Unfortunately, when I started conducting the study the admission rate went down and so recruiting of participants became a challenge and the data gathering period took longer than expected.

However, the purpose of the study was achieved. I discovered from the interviews the experiences of the primary caregivers. There was a difference between a primary caregiver and just a carer or a member of the family of the cancer patients. When entering the patients' rooms in the presence of the family, it was easy to identify the primary caregiver. They always looked so concerned, anxious and most of the time asked many questions. Despite all their emotions, they were always thankful and appreciated any information or updates given to them regarding care and patient progression. When it came to their caring role, primary caregivers became selfless, all their focus shifted to their ailing loved ones and they completely forgot about caring for themselves. They had no time; days became too short for them.

As I interviewed the participants, I noticed a few of them cried during the interviews and reported that they had never had time to reflect on themselves until the time of the interviews. Crying was helpful to them and 50% of the participants reported to be feeling much better emotionally and relieved after the interviews. Some of the participants said there was no need for counselling anymore, the interview had played a counselling role. They wished to see the findings of the study and were optimistic that the findings would make a difference in care of the caregivers. It was sometimes emotional listening to their stories, but this study taught me a lot about care of the caregivers.

It was painful to listen to some of the participants stories, and worst of all, having to listen to the stories again during transcription added more pain, however, I became stronger with each interview and was able to support them emotionally afterwards.

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APPENDIX A: Participant Information Sheet

Title: The experiences of primary caregivers caring for cancer patients admitted to a hospice

Telephone number(s): +27 712 981 474

Good day, my name is Tinalipi Sophinah Ketlogetswe, I am a masters' student in Oncology and Palliative Care at University of Witwatersrand, Faculty of Health Sciences, Department of Nursing. I would like to invite you to consider participating in a research study, entitled 'Experiences of primary caregivers caring for cancer patients admitted to a hospice'

1. To understand what is involved before you agree to take part in this study, it is important that you read and understand the following explanation of the purpose of the study, the study procedures, benefits, risks if any, discomforts and your right to withdraw from the study at any time.

2. If you have any questions, do not hesitate to ask me.

3. You should not agree to take part unless you are satisfied about all the procedures involved.
4. If you decide to take part in this study, you will be asked to sign this document to confirm that you understand the study. You will be given a copy to keep.

5. If you have a personal counsellor or psychologist, please discuss with or inform him/her of your possible participation in this study. If you wish, I can also notify them in this regard.

Length of the study and number of participants
The study will be performed in Johannesburg, South Africa
Participants will be enrolled at Houghton Hospice Wits
The participants will be 18 years and above.
The total amount of time required for your participation in this study will be a maximum of 45 minutes as a once off interview.

Unforeseen risks
No risks are anticipated in this study; however, you should immediately stop me if you are not feeling well emotionally and a counsellor in the facility will be asked to assist you.
Benefits

The potential benefit from your participation in this study may be emotional relief, support and counselling. However, you may not directly benefit from this study. Your participation in this study will contribute to nursing knowledge that may help other caregivers and improve the support and services that they receive.

Rights as a Participant in this Study-Your participation in this study is entirely voluntary and you can decline to participate, or stop at any time, without stating any reason. Your withdrawal will not affect your access to other medical and nursing care services.

Reimbursement for Study Participation -You will not be paid to participate in this study, it is entirely voluntary.

Ethical Approval

This clinical study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee. The 24hour telephone number through which you can reach me or another authorised person is 0712981474. If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Professor Lize Maree my supervisor at +27 (0) 11 488 4198/4272

Confidentiality

All information obtained during the course of this study, including personal data and research data will be kept strictly confidential. Data that may be reported in scientific journals will not include any information that identifies you as a participant in this study.

The information will be inspected by the University of the Witwatersrand, Human Research Ethics Committee (HREC), as well as my supervisor. I will keep a record of people who participated in the study and will keep the recordings of our interviews, together with a transcription of those recordings. Your name will not be on the recording or on the transcriptions, so that data will not be linked to your name. All data will be stored in a secure place and nobody except the research team will have access to your interview. Therefore, you hereby authorise me to release your personal information to my supervisor and the University of the Witwatersrand, Human Research Ethics Committee (HREC). These records will be utilised by them only in connection with carrying out their obligations relating to this clinical study.

APPENDIX B: Participant Informed Consent

I hereby confirm that I have been informed by the study Student _____ about the nature, conduct, benefits and risks of study “Experiences of caregivers caring for cancer patients admitted to a hospice”. I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details regarding my sex, age, will be anonymously processed into a study report. In view of the requirements of research, I agree that the data collected during this study can be processed in computerised system by the University or sponsor or on their behalf.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant

Printed Name Date and Time

I, _____ herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Study student

Printed Name Signature Date and Time

Witness

Printed Name Signature Date and Time

APPENDIX C: Consent for tape recording

Institution: University of Witwatersrand

Telephone number(s): +27 712 981 474

Title: The experiences of primary caregivers of cancer patients admitted to a hospice

Good day, my name is Tinalipi Sophinah Ketlogetswe, I am a masters' student in Oncology and Palliative Care at University of Witwatersrand, Faculty of Health Sciences, Department of Nursing Education. Thank you for considering my invitation in participating in this research study, entitled 'Experiences of caregivers of cancer patients admitted to a hospice'.

I am requesting for your permission to allow me to record our interview. Your name will not be on the recording or on the transcription, so the data will not be linked to your name. All data will be stored in a secure place and no one except the research team will have access to your interview. I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to have my interview recorded.

Participant

Printed Name Signature Date and Time

I, _____ herewith confirm that the above participant has been fully informed about the obligation involved in recordings of this study.

Study student

Printed Name Signature Date and Time

Witness

Printed Name Signature Date and Time

APPENDIX D: Demographic Information and Characteristics of the Participants

TITTLE: The experiences of primary caregivers of cancer patients admitted to a hospice

Demographic Information			
Age:		Relationship:	
		Gender of care giver:	
Marital status:			
Single			
Married			
Widow			
Employment status:		**Educational level:**	
Employed		None	
Unemployed		Grade 1-7	
Self employed		Grade 8-12	
		Higher education	
Period as Primary caregiver			
Age			
Patient Diagnosis			
Period of Sickness			
Gender of Patient			
Ethnicity (cultural group)			

APPENDIX E: Interview guide

To gather data, one question was asked '*Please tell me what it is like for you to take care of a very sick cancer patient?'* where after probes and prompting questions were used to encourage participants to clarify issues and expand on their experiences. These were determined by the participant's response to the main interview question. A digital voice recorder was used to record the interviews with permission from the participant.

APPENDIX F: Letter to the Hospice

APPENDIX F

University of Witwatersrand

Faculty of Health Sciences

School of Therapeutic Sciences

Private Bag 3 Wits

2050, Johannesburg, South Africa

28 March 2017

The Director

Hospice Wits, Houghton

50 2nd Avenue

Johannesburg, 2198

Dear Sir

RE: PERMISSION TO CONDUCT A RESEARCH STUDY IN YOUR ORGARNISATION

My name is Tinalipi Sophinah Ketlogetswe, A student at the University of Witwatersrand. I am enrolled in a masters' programme on Oncology and Palliative care. One of the requirements of my program is to conduct a research and write a report. I would like to conduct my study entitled: '**The experiences of primary caregivers of cancer patients admitted at a hospice'** at your hospice. Results of this study will help improve services and interventions targeted for caregivers in South Africa.

1

I am awaiting approval of the study by Human Research Ethics committee of the University of Witwatersrand and all obligations of the study will be adhered to. A Copy of the ethics clearance certificate will be will be sent to you once available.

I hope to hear from you in due course. For any clarifications please do not hesitate to contact me or my supervisor at +27 11 488 4272/4196

Yours Sincerely

Tinalipi Sophinah Ketlogetswe

Contact no: +27 712981474

Email: 1110602@students.wits.ac.za

APPENDIX G: Approval Letter from Houghton Hospice

Hospice Wits
no end to caring

Sr Gerda Labuschagne
Palliative Services Manager
50 2nd Avenue Houghton
Johannesburg
2198

12/06/2017

Department of Nursing Education
Faculty of Health Sciences
University of the Witwatersrand
7 York Road
Parktown 2193
Johannesburg

Good afternoon Mr, Kandidi,

RE: PERMISSION TO CONDUCT A RESEARCH STUDY AT HOSPICE WITS IPU.

On behalf of the Clinical department at Hospice Wits, I am writing to formally indicate our awareness of the research proposed by Tinalipi Sophinah Ketlogetswe, a student at the University of the Witwatersrand. We are aware that Tinalipi Sophinah Ketlogetswe intends to conduct her research by interviewing the primary caregivers of patience.

As Palliative services Manager I am responsible for employee relations. I grant Tinalipi Sophinah Ketlogetswe permission to conduct her research at Hospice Wits IPU.

If you have any questions or concerns, please feel free to contact my office at 011 483 9100.

Gerda Labuschagne
Palliative Services Manager
gerda@hospicewits.co.za

APPENDIX H: Approval Letter from Ethics Committee

R14/49 Ms Tinalipi Sophinah Ketlogetswe

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170472

NAME: (Principal Investigator)	Ms Tinalipi Sophinah Ketlogetswe
DEPARTMENT:	Nursing Education Houghton Wits Hospice
PROJECT TITLE:	The Experiences of Primary Caregivers Caring for Cancer Patients in the End-of-Life Phase of the Trajectory
DATE CONSIDERED:	05/05/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof Lize Maree
APPROVED BY:	Professor P. Cleaton-Jones Chairperson, HREC (Medical)
DATE OF APPROVAL:	24/07/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date 26/07/2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX I: Approval of Research Title

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

02 February 2018
Person No: 1110602
TAA

Mrs TS Ketlogetswe
P.o. Box 81767
00267
Botswana

Dear Mrs Ketlogetswe

Master of Science in Nursing: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of **Master of Science in Nursing** has been approved:

From:	**The experiences of Primary Caregivers of cancer patients in the End-of-life phase of the disease Trajectory at a hospice**
To:	**The experiences of primary care givers of cancer patients admitted to a hospice**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX J: Work Certificate of Language Edition

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Prof L. Maree, RN DCUR (Pret)
Address	Wits Dept of Nursing Education
Date	14/02/2018
Subject	The experiences of caregivers of cancer patients admitted to a hospice
Ref	LM/GS/056

I, Gill Smithies, certify that I have edited the following for language and style,

Research Study: The experiences of caregivers of cancer patients admitted to a hospice,

to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies

14/02/2018

APPENDIX K: Plagiarism Declaration Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Tinalipi S. Ketlogetswe (Student number: 1110602) am a student registered for the degree of MSc Nursing in the academic year 2018.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: [signature] Date: 27/02/2018