EXPERIENCES OF FAMILIES REGARDING CARING FOR FAMILY MEMBERS WHO ARE TERMINALLY ILL

by

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DECLARATION

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ABSTRACT

THE EXPERIENCE OF FAMILIES REGARDING CARING FOR FAMILY MEMBERS WHO ARE TERMINALLY ILL

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Caring for terminally ill patients can be regarded as an important public health concern in South Africa. In Sub-Saharan Africa, the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) and cancer are the most pressing concerns, with 22.5 million infected people in 2009, which means that two thirds (68%) of the global population is living with HIV/AIDS (Pool, 2011:10). It is generally known that South Africa is a leading country in Sub-Saharan Africa in the provision of palliative care. Previous research studies also revealed that many terminally ill patients are voicing the desire to die at home instead of in a hospital or in other health care institutions, which place an unbearable pressure on families. Family caregiving is generally provided by close family members of the terminally ill patient. Providing care to a family member with a terminal illness at home presents with several challenges, such as the fact that taking care of the terminally ill patient is time consuming, which may lead to feelings of social isolation.

The goal of the research study was to explore the experiences of families regarding caring for family members who are terminally ill at home in the community of Ehlanzeni District in the Mpumalanga Province. The guiding research question was: What are the experiences of families regarding caring for family members who are terminally ill living in Ehlanzeni District in the Mpumalanga Province?

A qualitative research approach was followed, with a collective case study as research design. The population for this study was family members who lived with a terminally ill patient. Non-probability, purposive sampling was applied to generate a sample. The sample size of the study was 11 participants between the ages of 18 and 62 years. Semi-structured interviews were used to collect the data, supported by an interview schedule to explore the experiences of family members regarding caring for terminally ill family members. All interviews were voice recorded with the consent of the participants. The data that was gathered by the researcher were analysed and themes and sub-themes were identified.

The empirical findings of the study indicated that the physical demands of family caregiving for a family member with a terminal illness at home are often too much for families to handle on their own without the support of other professional systems. It also revealed that these caregivers, who are mostly females, often present with poor health themselves because of the pressure they experience during the caring process. Some of the family caregivers feel isolated, as they do not have enough time for themselves or for the other family members due to the fact that family caregiving demands almost all of their time. Some of these caregivers face financial constraints, their children's school performance decreases, and they are living in poverty-stricken conditions. Some of the participants indicated that family caregiving does have a positive side too, namely that they can take care of a family member, which is a symbol of love and respect.

Conclusions and recommendations were formulated which focus primarily on the role of health professionals, including social workers, in providing a quality service to the terminally ill patients and their families. Themes for further research in this professional field were indicated.

List of key terms:
Terminally ill patient, palliative care, home-based care

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ABBREVIATIONS

AND	A natural death
AIDS	Acquired Immune Deficiency Syndrome
HBC	Home-based care
CRD	Chronic renal disease
CRF	Chronic renal failure
CVA	Cerebrovascular accident
CVD’s	Cardiovascular diseases
DNAR	Do-not-attempt-resuscitation
DNR	Do not resuscitate
ESRD	End-stage renal disease
HIV	Human Immunodeficiency Virus
ICU	Intensive care unit
IPF	Idiopathic pulmonary fibrosis
MI	myocardial infarction
MS	Multiple sclerosis
PCA	Person-centred approach
PP	Primary progressive
PTSD	post-traumatic stress disorder
RR	Relapsing remitting
SP	Secondary progressive
TB	Tuberculosis
WHO	World Health Organization

1. CHAPTER 1: GENERAL INTRODUCTION

1.1 INTRODUCTION

Terminally ill patient care is an important public health concern in South Africa. In Sub-Saharan Africa, the Human Immunodeficiency Virus (HIV) or Acquired Immune Deficiency Syndrome (AIDS) and cancer are the most pressing concerns, with 22.5 million infected people in 2009, which means two thirds (68%) of the global population is living with HIV/AIDS (Pool, 2011:10). These people may have a short life expectancy and because of that, they are dependent on others to care for them until they die. Most patients with terminal illnesses have no hope of recovering from their illnesses and are therefore in need of comfort and care, which includes the right to die in peace and with dignity. It is generally known that South Africa is a leading country in Sub-Saharan Africa in the provision of palliative care (Kell & Walley, 2009:208). However, it became evident that the demands of caring overwhelmed the health care workers and hindered the delivery of quality palliative care to terminally ill patients. The main aims of caring for terminally ill patients is to improve their quality of life, comfort them through hygienic action, and raise the patients' morale (Robbins, 1989:38).

South African public hospitals are heavily challenged (South African National AIDS Council, 2011:109), as over 80% of the country's population have no medical aid cover and are forced to seek treatment in Government clinics and hospitals (South Africa, 2009). The National Department of Health's Ten Point Plan strategy (Department of Health, 2010) estimated the costs of uninsured people in the public sector at R85 billion, as opposed to all the insured South Africans in the private sector worth R113 billion. According to different researchers, there is a growing recognition of the suffering of patients who are experiencing terminal illnesses and the need to improve the quality of their lives as their illnesses progress. Sherman (1998:357) indicates that the result of this is that most of these patients become the responsibility of their family members who have to take care of them until they die. However, these families do not always have the means to look after these patients, which may put too much pressure on the family members to take care of them in a humane manner (Public Health Policy, 2007:34). Furthermore, it is already recognised in practise that the challenges of caring for the terminally ill have not yet been identified as a public health priority, particularly in developing countries. With reference to the latter, the aim of this study was to explore the experiences of families regarding caring for family members who are terminally ill. Participants will be given the opportunity to share their experiences and challenges regarding caring for their family members who are terminally ill.

The purpose of the research was to explore the experiences of families regarding caring for family members who are terminally ill in the community of Ehlanzeni District in the Mpumalanga Province.

The following concepts were used in this study:

- **Terminal illness**: Terminal illness can be defined as a status assigned to a person who has been diagnosed with an illness and is expected to die within a certain time frame, usually six months (World Health Organization, 2012:21). A terminal illness can also be referred to as an illness or injury that will inevitably result in the death of the patient. The South African Law Commission's proposed Draft Euthanasia Bill, similarly defined terminal illness as an illness or injury which in the opinion of at least two competent medical practitioners (a) will inevitably result in death of the patient and which is causing the patient severe suffering, or (b) is causing the patient to be in a persistent, irreversible, unconscious condition (Law of Euthanasia, 2014).
- **Patient**: A patient is an individual who is receiving needed professional services that are directed by a licensed practitioner of the healing arts toward the maintenance, improvement, or protection of health or lessening of illness, disability, or pain (US Centres for Medicare & Medicaid Services, 2008:8). The patient with a terminal illness may require significant assistance on a daily basis. A patient's needs may range from assistance with basic functions, such as maintaining hygiene standards and preparing and consuming appropriate nutrition, to the administration of medication, emotional support, counselling, and religious guidance (McQuoid-Mason & Dada, 2011:414).
- **Death**: Death is described as the final cessation of vital functions in an organism; the ending of life (Allen, Simelelela & Makubalo, 2009:91). Death comes to everyone and therefore remains an important phenomenon in all

cultures and with all people, religious or not. For black cultures in rural communities, it is a concept to be feared and not spoken about.

- **Palliative care**: Palliative care is often referred to as comfort care and is primarily directed at providing relief to a terminally ill person through the management of symptoms and pain (World Health Organization, 2012:13).
- **Grief**: Grief is a process in which the bereaved remembers the loved one who has died and to adjust to his/her life without them. Although a grief reaction is different for everyone, the phases of grief typically involve emotional and psychological reactions in the griever that include affective, cognitive, physiological, and behavioural symptoms (Worden, 1991:71).
- **Family**: Richter (2007:4) defines families as societal groups that are related by blood (kinship), marriage, adoption, or affiliation with close emotional attachments to each other that endure over time and go beyond a particular physical residence. Furthermore, a family is a group of two or more people (one of whom is the householder) related by birth, marriage, or adoption and who are residing together (Belsey, 2005:11). One of the main functions of a family is to provide its members with love and affection. Peterson (2009:34) indicated that the role of the family is also to fulfil important functions for their members, such as membership, economic support, nurturance, socialisation, and the protection of vulnerable members.

1.2 THEORETICAL FRAMEWORK

The theoretical framework that informed the study was the person-centred approach (PCA).

The PCA is regarded as most relevant for this study considering the fact that it focuses on the different experiences, emotions, needs, behaviour, and perceptions of individuals. Rogers (1987:498) states that people are unique and have different perceptions, therefore it is important to understand their experiences, the perceptions they have of themselves, and how they believe they are being affected. Therefore, this approach was most appropriate as it aims to reach the goal of the study by exploring the experiences of families regarding caring for family members who are terminally ill.

Considering the fact that the families are the ones who have the experiences in terms of taking care of their family members who were terminally ill, and that they are in a position to know what their needs and challenges are, the researcher gave them enough opportunity to share their experiences during the interviews, based on their social, psychological, financial, and physiological needs. The researcher therefore never judged or labelled the participants, but rather explored and accepted their realities and experiences as the truth.

The researcher used the PCA to approach the participants with the necessary empathy, congruency, and acceptance which were so important during the facilitation of the research process. Furthermore, it supported the researcher to understand the real feelings, experiences, and perceptions of the participants. Prince (2006:49-56) supports the latter by confirming the importance of the PCA in health settings, as it has the potential to promote meaningful physical and emotional comfort. A core concept behind the PCA is the need to treat people with, and preserve, dignity in care settings. People with a terminal illness were also regarded by the researcher as people with sensitive needs in terms of their condition, symptoms, and life expectancy.

1.3 LITERATURE REVIEW

The National Cancer Registry (2014:7) stated that the term ‘terminal illness’ or ‘chronic illness’ is assumed to encompass the population of patients of all ages and a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects their daily functioning or will predictably reduce their life expectancy. In the context of a terminally ill patient, a caregiver generally refers to the person or persons in the home who are responsible for the primary care of the dying patient. In many families the caregiver is a patient’s wife, husband, mother, daughter, sister, or other family member (Gallagher-Allred, 2009:57).

There is no doubt that taking care of a terminally ill family member has a physical, psychological, and financial impact on the family system. The physical demands on families are closely related to medical variables, such as the stage of the disease, the level of symptomatology, the functional ability of the patient, and the side effect profile. The psychological impact of terminal illnesses like cancer can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, families may find that taking care of the terminally ill patient is time-consuming and can lead to feelings of social isolation (Rocker, Puntillo, Azoulay & Nelson, 2010:152-153).

Fakhoury and McCarthy (2007:161) state that terminally ill patients in general spend as much as 90% of their time at home. Home is usually where people would like to be when ill and where they would like to die. The most difficult challenge that family members need to face is the moment when the patient enters the critical care stage and they realise that they have to face death and the implications that it will have for the family (Rocker et al., 2010:150-152).

In a study by Gallagher-Allred (2009:59), it was indicated that many patients are voicing their wish to die at home instead of in the hospital or in other health care institutions. Patients and family members often experience the fear of performing the task of taking care of terminally ill family members due to the uncertainty of what the future will hold and what to do when an unmanageable crisis develops and they are unable to obtain support.

Family members are often unable to distinguish a serious problem from a trivial one and typically interpret small or large changes in the patients. They fear not knowing what to do in emergencies, or at the time of death. Furthermore, family members are often concerned about what effects taking care of terminally ill patients will have on other family members.

Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore, and maintain a person’s maximum level of comfort, function and health, including care towards a dignified death (Borochowitz, 2011:42). The main aim of home-based care (HBC) is to provide effective community-based care and support. Home care services can be classified into different categories, namely: preventive, promote, therapeutic, rehabilitative, long-term maintenance, and palliative care. The World Health Organization (WHO, 1999:97) states that community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life, and creates responsibilities. The WHO (1999:209) explains that the community home-based care (CHBC) programme promotes caregiving to individuals in their natural environment, i.e. in their home, by family members, supported by skilled social welfare officers and communities, to meet spiritual, material and psychosocial needs, because taking care of terminally ill patients and their families remain a crucial role. The target group for this programme is any person with a terminal illness or full-blown AIDS, and chronically-ill persons.

Hornillos and Crespo (2012:126) indicate that a support group refers to a mutual aid group and is one of the most widely used and popular interventions with family caregiving. It has been identified as a basic form of psychosocial support for those families caring for terminally ill family members. Support groups also create an opportunity for the family caregivers to improve the condition of their environment and provide them with skills to manage a highly demanding situation to relieve their emotional distress, and maintain their quality of life (Social Tract, 2010:51). Support groups have a variety of purposes and goals. It provides support, education, socialisation and self-help, and enhances the family caregiver’s sense of self-esteem and assertiveness. Furthermore, it assists the group members to vent strong feelings such as anger, regret, and shame. Support groups provide opportunities for family caregivers to learn powerful lessons about coping effectively with their family members with terminal illnesses. The majority of group members discover an improved sense of interpersonal confidence and self-worth from sharing their experiences and expertise with fellow group members (Hornillos & Crespo, 2012:137).

1.4 RATIONALE AND PROBLEM STATEMENT

There is a general paucity of information regarding the actual experiences of families caring for terminally ill patients at home specifically. Although there have been some studies focusing on the status of caring for patients within hospitals and hospices in South Africa and Sub-Saharan Africa, this proposed study can highlight the challenges that family members have to face when they are forced to take care of terminally ill family members at home without any external support.

As the majority of terminally ill patients are being discharged from hospitals to die at home, a large number of families are struggling in terms of providing proper care due to a lack of knowledge and financial support, as well as the emotional effect it has on the functioning of the family system. It was also the experience of the researcher that home care for terminally ill family members may have an effect on the rest of the family members' psychological, mental, physical, and financial well-being. Kristjanson (2004:49) confirms the latter and mentions that the needs of family members who have to take care of terminally ill family members at home often stay unmet.

Families who have to take care of terminally ill family members at home need support and counselling on a regular basis to enable them to cope with the impact of the diagnosis (Kristjanson, 2004:49). It was thus important during the research process to explore the experiences of family members regarding the challenges that they have to face while taking care of terminally ill family members at home. The data that were collected in this study highlighted the needs of these families, which have to be taken note off. The following research question will guide the researcher in this study:

What are the experiences of families regarding caring for family members who are terminally ill living in Ehlanzeni District in the Mpumalanga Province?

1.5 GOAL AND OBJECTIVES

1.5.1 Goal of the study

The goal of the study was to explore the experiences of families regarding caring for family members who are terminally ill in the community of Ehlanzeni District in the Mpumalanga Province.

1.5.2 Objectives of the study

In order to achieve the research goal, the following were the objectives of the study:

- To do a thorough literature study on family caregiving for a terminally ill patient, as well as the needs and challenges faced by family members while taking care of these patients at home.

- To explore the challenges family members are facing in taking care of terminally ill family members at home.
- To formulate recommendations based on the outcome of the study regarding support for family members that have to take care of terminally ill patients.

1.6 OVERVIEW OF THE RESEARCH METHODOLOGY

The study was qualitative in nature, as the researcher focused on the experiences of family members who have to take care of other family members at home who are terminally ill. Applied research was the most suitable type of research to follow in this study, while a case study was the most suitable research design. It assisted the researcher to gain a better understanding of the experiences of families regarding caring for family members who are terminally ill.

The researcher used the collective case study as the appropriate design to attain the goal of the study. The collective case study was also chosen due to the fact that multiple cases were involved in the study.

The population in this study included family members who take care of terminally ill family members and who reside in the Ehlanzeni District in the Mpumalanga Province. Non-probability sampling, namely purposive sampling, was applied during the recruitment of participants. Eleven participants were recruited from Nelspruit Hospice in the Ehlanzeni District, Mpumalanga, according to specific criteria. All the patients had been diagnosed with terminal illnesses, discharged from the Rob Ferreira Provincial Hospital and referred to the Nelspruit Hospice for palliative care, due to other advanced clinical stages. The participants of the study were selected according to the following criteria:

- Male or female family members who were willing to participate in the study.
- Family members who were directly involved in caring for family members at home that have been diagnosed by a medical doctor with a terminal illness.
- Participants who were between the ages of 18 and 62 years.
- Participants whose family members have been discharged from the Rob Ferreira Provincial Hospital for at least three months.

For the purpose of this research study, face-to-face, semi-structured interviews were used as data collecting method to generate detailed data on the experiences of families regarding caring for terminally ill family members. The interview schedule consisted of the different themes that focused on the experiences and challenges faced by family caregivers regarding caring for their terminally ill family members. All the interviews were audio recorded. The data analysis process was utilised as posited in De Vos (2011:339) and themes and sub-themes were identified.

The researcher used credibility, transferability, conformability, and dependability in establishing the trustworthiness of the research (Polit & Beck, 2008:537). Furthermore, the researcher utilised various strategies in order to prioritise the voice of the participants in the research outcome (Babbie & Mouton, 2008:277). The strategies are as follows:

- reflexivity;
- peer reviewing; and
- member checking

A pilot study was undertaken to pre-test the data collection instruments. The aim was to determine whether the interview schedule was suitable (Strydom & Delport, 2011:394-395) for the specific study. Two participants were interviewed during the pilot study who were not included in the main study.

Ethical issues were taken seriously throughout the research process in order to protect participants from any possible harm.

More detailed information concerning the research methodology is captured in Chapter 3.

1.7 LIMITATIONS

Due to the fact that only a small portion of family caregivers from the rural areas and disadvantaged families was included in the study, the results cannot be generalised. However, the results should provide a clear indication of what could be expected from a similar sample.

The study had the following limitations:

- The sample consisted of 11 family members who were caring for terminally ill family members at home, therefore the findings cannot be generalised.
- The researcher could not access the views of the other cultural groups due to their unwillingness to participate in the study.
- The researcher had to rely on international studies to control the findings, as there was limited South African-based literature available to consult in this regard.
- Most of the participants were female, limiting the perspectives of male family members who have to care for terminally ill family members.

1.8 CONTENT OF THE RESEARCH REPORT

Chapter 1: Consists of a general introduction to the study, including the problem formulation, goals and the objectives of the study, the research question, the research methodology, and possible limitations.

Chapter 2: Provides an in-depth literature review on home care of terminally ill patients by their family members, different forms of palliative care, the public policy on the role of the government in palliative care, the importance of support groups and community home-based care services, the role of family caregiving, and the needs of both the patients and family members, as well as the effect of terminal illness on the caregiving system.

Chapter 3: Discusses the methodology of the study and the research design, the aim of the study, the research questions, the sampling procedure and ethical considerations, and data collection and analysis. The research findings were discussed according to themes and sub-themes, and were also outlined and interpreted.

Chapter 4: Provides a summary, conclusion, and recommendations based on the outcome of the study. It also discusses whether the goals and objectives of the study were achieved. Conclusions were drawn and recommendations were made for future researchers, health care professionals, and social workers in the field of caring for terminally ill patients and their families.

CHAPTER 2: HOME CARE OF TERMINAL ILL PATIENTS BY THEIR FAMILY MEMBERS

1.9 INTRODUCTION

Terminal illness is a disease that cannot be cured or adequately treated and that is reasonably expected to result in the death of the patient within a short period of time. This term is more commonly used for progressive diseases such as cancer or advanced heart disease, HIV/AIDS and chronic renal failure (CRF). In popular use, it indicates a disease that eventually ends the life of the sufferer (Pass & Morrison, 2006:117). Patients who have such an illness may be referred to as terminal patients, terminally ill or simply terminal. Often a patient is considered terminally ill when their estimated life expectancy is six months or less, under the assumption that the disease will run its normal course. The six-month standard is arbitrary, and at best available estimates of longevity may be incorrect. Consequently, though a given patient may probably be considered terminal, this is not a guarantee that the patient will die within six months.

Barry and Henderson (1996:161) stated that many terminally ill patients go through periods when their illness temporarily interferes with the desire or ability to eat and drink. Among the most common causes are the side effects of chemotherapy for the treatment of cancer and reversible physical abnormalities involving the mouth, throat, oesophagus, stomach, or intestinal tract. During such periods, artificial nutrition and hydration through feeding tubes or by intravenous fluids is clearly justified. McQuoid-Mason and Dada (2011:156) stated that it is unfortunate and of particularly concern in the South African context where there are indications that thousands of people are not enjoying good health and are in fact facing life-threatening or potentially life-threatening medical diagnoses. Thus, the question of what the right to health care means in respect of terminally ill South Africans, has not enjoyed the attention it deserves, despite the fact that terminally ill patients have a right to palliative care and may in certain instances be eligible to such care at the state's expense.

According to World Health Statistics, it is estimated that of the 58 million people who die every year globally, 35 million will experience a prolonged, advance illness. Unfortunately, South Africa is not exempt from this reality. The impact of the HIV/AIDS pandemic and predictions by the Cancer Association of South Africa that, within half a century, the number of annual cancer diagnoses in South Africa could soar from approximately 100 000 to half a million (WHO, 2012:34).

1.10 DEFINING OF KEY CONCEPTS

1.10.1 Grief

Grief is a process in which the bereaved remembers the loved one who has died and to adjust to his or her life without them. Although a grief reaction is different for everyone, the phases of grief typically involve emotional and psychological reactions in the griever that include affective, cognitive, physiological, and behavioural symptoms (Worden, 1991:71).

1.10.2 Family

Richter (2007:4) defines families as societal groups that are related by blood (kinship), marriage, adoption, or affiliation with close emotional attachments to each other that endure over time and go beyond a particular physical residence. Furthermore, a family is a group of two people or more (one of whom is the householder) related by birth, marriage, or adoption and residing together (Belsey, 2005:11). One of the main functions of a family is to provide its members with love and affection. Peterson (2009:34) indicated that the role of the family is also to fulfil important functions for their members, such as membership, economic support, nurturance, socialisation and protection of vulnerable members.

1.10.3 Terminal illness

Terminal illness can be defined as a status assigned to a person who has been diagnosed with an illness and is expected to die within a certain time frame, usually six months (WHO, 2012:21). Terminal illness can also be referred to as an illness or injury that will inevitably result in the death of a patient. The South African Law Commission proposed Draft Euthanasia Bill, similarly defined terminal illness as an illness or injury which in the opinion of at least two competent medical practitioners (a) will inevitably result in death and which is causing the patient severe suffering, or (b) is causing the patient to be in a persistent, irreversible, unconscious condition (South African Law Commission of Euthanasia, 1997).

1.10.4 Patient

A patient is an individual who is receiving needed professional services that are directed by a licensed practitioner of the healing arts toward the maintenance, improvement or protection of health or lessening of illness, disability or pain (US Centres for Medicare & Medicaid Services, 2008:8). The patient with terminal illnesses may require significant assistance on a daily basis. A patient`s needs may range from assistance with basic functions, such as maintaining hygiene standards and preparing and consuming appropriate nutrition, to the administration of medication, emotional support, counselling and religious guidance (McQuoid-Mason & Dada, 2011:414).

1.10.5 Death

Death is described as the final cessation of vital functions in an organism, the ending of life (Allen, Simelelela & Makubalo, 2009:91). Death comes to everyone and therefore remains an important phenomenon in all cultures and with all people, religious or not, and is a concept to be feared, and not spoken about.

1.10.6 Palliative care

Palliative care is often referred to as comfort care and is primarily directed at providing relief to a terminally ill person through the management of symptoms and pain (WHO, 2012:13).

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses, 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 (WHO, 2008:38).

The World Health Organization (2008:46) elaborated on the principles of palliative care as follows:

- Provides relief from pain and other distressing symptoms.

- Affirms life and regards dying as a normal process.
- Intends neither to hasten, nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage.
- Distressing clinical complications.

1.10.7 Patient populations served

The National Cancer Registry (2014:7) stated that the term terminal illness or chronic illness is assumed to encompass the population of patients of all ages and a broad range of diagnostic categories, who are living with a persistent or recurring condition that adversely affects their daily functioning or will predictably reduce life expectancy. Based on this definition, the patient population refers to the following:

- Children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments and or long-term care with support from others for the activities of daily life.
- People of any age with acute, serious, and life-threatening illnesses (such as severe trauma, leukaemia, or acute stroke), where cure or reversibility is a realistic goal, but the conditions themselves and their treatments pose significant burdens and result in poor quality of life.
- People living with progressive chronic conditions (such as peripheral vascular disease, malignancies, chronic renal or liver failure, stroke with significant functional impairment, advanced heart or lung disease, frailty, neurodegenerative disorders, and dementia).

- People living with chronic and life-limiting injuries from accidents or other forms of trauma.
- Seriously and terminally ill patients (such as people living with end-stage dementia, terminal cancer, or severe disabling stroke), who are unlikely to recover or stabilise and for whom intensive palliative care is the predominant focus and goal of care for the remainder of their lives.

The NCR (2014:19) indicated that there are several clinical models that have demonstrated quality care for patients and families. They include a variety of disciplines that collaborate to provide quality care. These include:

- Hospice Care: a well-established program to provide patients with a prognosis of six months or less. As delineated within the Medicare Hospice Benefit, these services can be provided in the home, nursing home, residential facility, or in an inpatient unit.
- Palliative Care Programs: institutional based programs in the hospital or nursing home to serve patients with life-threatening or life-limiting illnesses. Occur in hospital settings (academic, community, rehabilitation) and skilled nursing facilities. Provide services to patients anywhere along the disease continuum between initial diagnosis and death. Can include a consultation team, a fixed-bed unit, or a swing-bed unit.
- Outpatient Palliative Care Programs: occur in ambulatory care settings to provide continuity of care for patients with serious or life-threatening illnesses.
- Community Palliative Care Programs: occur in communities as consultative teams who collaborate with hospices or home health agencies to support seriously ill patients who have not yet accessed a hospice.

1.11 TYPES OF PAINS

Direct tumour involvement is the most common cause of pain to the terminally ill patient, especially to cancer patients (Saunders, Baines & Dunlop, 2010:13). In most cases the pain is nociceptive, caused by mechanical and chemical stimuli in bone, viscera and conducted along intact somatosensory pathways. However, a significant proportion of cancer pain is neuropathic caused by damage in the central or peripheral nervous system (Saunders et al., 2010:14). Some of these common pains can be described as follows:

- Bone pain: certain bone metastases produce prostaglandins, which sensitise no-ciceptorsand and lead to pain. The pain is usually associated with local tenderness and is exacerbated by movement.
- Neuropathic pain: this often occurs with tumour infiltration of the brachial plexus or lumber plexus, or injury to nerve roots due to vertebral metastases. However, neuropathic pain can occur with many other types of damage to the central or peripheral nervous system and therefore many further pain syndromes occur. Nerve pain is felt in the appropriate dermatome and, it is often described as burning or shooting in nature and is associated with motor sensory or autonomic changes.
- Visceral pain: this is due to tumours involving abdominal or pelvic organs.
- Lymphedema: this occasionally follows surgery and radiotherapy and is, often due to recurrent tumour.
- Intestinal colic from constipation or malignant obstruction.
- Headaches from raised intracranial pressure.

Saunders et al. (2010:18), indicates that significant proportion of the pain experienced by patients with advanced cancer is due to a non-malignant cause. Examples are as follows:

- Pain associated with cancer treatment: a thoracotomy scar may continue to be painful for months or years after surgery. Radiation therapy can cause immediate problems such as aesophagitis or long-term problems such as radiation fibrosis.
- Pain caused by debility: patients with terminal disease are often bed or chair bound and develop the aches of pains being immobile. Constipation is common and bedsores develop rapidly as can thrush infections of the mouth.
- Other painful diseases: elderly patients often have other painful conditions, such as arthritis or piles.

1.11.1 Other forms may be components of total pain

Saunders et al. (2010:45), indicate that other than the physical aspects of terminal care, there are more subtle and complex problems to attend to.

The health care providers and caregivers have to take note of the following:

- **Mental pain**: Saunders et al. (2010:47), state that any illness causes anxiety, especially one that becomes more serious despite a variety of treatments until it is patently life threatening. Many patients still tend to be left alone with their fears or only receive reassurances which they suspect are false. Mental suffering is likely to be enhanced by any physical distress. Isolation adds to all sufferings, particularly to the feelings of failure and the sense of guilt suffered by many dying patients. Sensitive honesty engenders trust and can be supportive to both patient and family. Most human beings have the capacity to come to terms with their circumstances, which they retain even as death approaches. Thus for some it is a struggle that is deeply painful to watch, whilst others appear to hold quite contradictory feelings in an uneasy balance. Saunders et al. (2010:47), state that anyone who is faced with disaster or bad news tends to react initially with disbelief or denial. This is difficult to sustain and as it begins to waver, a patient may display yearning and protest similar to the restless pining of early bereavement. They may feel angry about what is happening to them and project this to on their treatment and to those giving it to them, and on to their families. These are feelings which can be worked through by patients if they can be expressed to people who understand something of the reason for the reaction and do not react by offended silence or withdrawal. It is at this point that the help of a Social worker or any other professional person can act as a back up to support the ward team. When patients appear to give up hope, they often turn their anger inward and lapse to depression and despair. Dying is not a psychiatric illness and does not always call for specialised skills in counselling.
- **Social pain**: Saunders et al. *(*2010:50), indicate that when an illness has a foreseeable end, it is true that many families will come to grips with the situation and will wish to look after a dying relative at home for as long as possible. Time spent with the family soon after hearing the poor prognosis will

help to establish or reaffirm trust and confidence. An explanation of the probable progress of the disease and what can be done to control pain, as well as a discussion of the actual process of dying will be needed. Families have the right to be present at this time, both cared for and caring, and their unique role must be emphasised and reinforced. The Social worker and a minister may still be much involved with those who react aggressively to their pain or are overwhelmed by their feelings.

- **Spiritual pain**: Saunders et al. (2010:50), indicate that many patients need help to face feelings of guilt and worthlessness that can truly be described as spiritual pain, sometimes amounting to deep anguish. Spiritual concerns need to be supported as much as physical and psychosocial issues in order to assist in recognising the purpose of meaning at the end of life. When treating terminally ill patient, health care providers must acknowledge the spiritual dimension as the integral part of the dying process.

1.11.2 Different forms of palliative care

Palliative care can be divided into these following categories:

1.11.2.1 Hospice care

The WHO (2012:89) defines hospice care as a form of palliative care provided to patients who are expected to live six months or less and who are no longer receiving treatment for the cancer. The goal of hospice care is to help patients and their families cope with the physical and emotional effects of death and dying. Because many patients with advanced cancer continue to receive cancer treatments throughout the course of their illness, they may not be eligible for hospice care. Different states have different policies regarding hospice care for patients, and some states do allow for cancer treatment and hospice care to be given at the same time. However, regardless of whether patients are eligible for hospice while receiving cancer treatments, they can continue to receive palliative care services. Hospice services are often focused on providing the support needed for care at home, but both palliative and hospice services may be provided in a hospital or in a private care facility (WHO, 2012:98).

Unlike a hospital, a doctor is not in the hospice centre all the time, but plans for end-of-life care can be arranged ahead of time, so that when the time comes, care can be provided as needed without first consulting a doctor. If the dying person has lived in the facility for a while, the staff and family have probably already established a relationship with each other. This can make caring for the patient feel more personalised than in a hospital. As in a hospital, privacy may be an issue (WHO, 2012:201).

The researcher's comment on palliative care is that, hospice care is an end-of-life care provided by health professionals and volunteers. They provide medical, psychological and spiritual support with the goal to help people who are dying, to experience peace, comfort and dignity. The caregivers in a hospice setting try to control pain and other symptoms so that a person can remain as alert and comfortable as possible. Hospice programs also provide the following support to the family of the patient:

- **Home care**: This means the provision of health care services in a patient's home that are intended to restore and maintain the patient`s optimal level of well-being in a familiar environment. The advantage of home care to terminally ill patients include maintaining the continuity of long-term habits, creating comfort, and being surrounded by family and friends that have being important to the dying patients throughout life. The disadvantage of home care is the lack of resources as compare to in the hospital. (Gallagher-Allred, 2009:59). Taking care of patients at home usually means that the terminally ill family member retains a larger degree of independence and personal power. However, another disadvantage of home care is also significant to the life of the family. In many family systems the patient`s presence dominates family life and disrupts the usual family routine in the family system. The latter often creates some feelings of guilt for the ill family members, as they feel they burden the family unnecessary. Finally, even though a tremendous amount of love may be present, there are some people who cannot tolerate the ambience of a sickroom or the ever-present threat of death (Gallagher-Allred, 2009:59).

According to the US Department of labour (2009:16), social workers have an important role in facilitating the transition of patients from the hospital or long-term care facility to home and to coordinate the provision of the following required home care service:

- **High care**: Lilly, De Meo & Sonna (2011:198) explain that the primary goals of high care medicine are to help patients survive acute threats to their lives while preserving and restoring the quality of those lives. These goals are frequently achieved, with approximately 75% to 90% of patients admitted to an intensive care unit (ICU). Even so, the ICU and high care facilities have become a common place to die, studies show that 22% of all deaths in the United States of America (USA) now occur in or after admission.

The Agency for Health care and Research Quality (2011:63) recommend a few ways to improve the delivery of palliative care in high care:

- **Patient and family centred decision making**: Patients and families must be given sufficient time to reach decisions at the end of life, and information should be delivered in ways that are sensitive to the patient's cultural, religious, and language needs.
- **Communication**: Communication skills are an important component of high-quality critical care, and there is increasing evidence regarding the importance of this skill for family outcomes. There is also increasing evidence supporting specific approaches that can improve communication and family experiences.
- **Continuity of care**: Caring for family members is an important part of caring for the critically ill patient. Family-centred care is based on the values, goals, and needs of the patient and family, including their understanding of the illness, prognosis, and treatment options and their expectations and preferences for treatment and decision-making.
- **Emotional and practical support of patients and families**: Supporting families through the death of a loved one in the ICU frequently involves guiding them through "hoping for the best and planning for the worst."
- **Symptom management and comfort care**: More than 50% of seriously ill hospitalised patients report some level of pain. Pain in the ICU is often related to iatrogenic causes, procedures, and interventions. Moderately or severely uncomfortable procedures that are commonly performed in the ICU include suctioning, turning, catheter insertion, wound care, and the presence of

endotracheal tubes. Minimising or eliminating iatrogenic sources of pain should be part of the pain relief plan. When patients cannot self-report their degree of pain, standardised scoring systems based on physiologic variables and behavioural observations can provide an objective basis for pain management.

1.11.3 Challenges in the field palliative care

Kim (2011:185) explains that the terminal illness issues are one of the top 10 health care ethics challenges facing people and also stated that care is unfortunately merely limited to terminal ill patients suffering from cancer and others. The following challenges can be mentioned:

- **Misconception**: Palliative care is applicable to the early course of illness, in conjunction with other therapies such as chemotherapy or radiation therapy, intending to prolong life and enhance the quality of life. According to the WHO (2012:96) palliative care is a n approach that improves the quality of life of patients and their families facing the problems associated with life threatening illnesses through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual of nature. It is generally a misconception that only people who are terminally ill and those who are beyond treatment, need palliative care.
- **Information gap**: Kim (2011:192) specified that death and dying is not a failure, but the most natural thing and sure event in life. There is a known custom in many societies and cultures that indicates one does not talk about imminent death with a terminally ill patient. Patients may not have discussed end-of-life decisions and wishes with their families while they were still mentally competent. Family members often do not want to be the ultimate decision makers when death is inevitable. Health care professionals in intensive care unit may experience some challenges in supporting patients and families due to a lack of information (Lasker, 2013:18).
- **Pain**: Pain is the dominant symptom in the advanced stages of diseases (Kholsa, Patel & Sharma, 2012:239). Pain can make a patient anxious, uncomfortable and impatient. Kim (2011:192) states that family members are repentant with sorrow due to the miserable death of their loved ones. Pain

relief can be successfully achieved by the scientific and holistic approach of analgesic administration in palliative care.

- **Physician Value**: The National Health and Medical Research Council (2011:44) explain that the debate over influence of physician judgment on patient autonomy at end-of-life care has long been studied. These studies suggest that decisions regarding terminal patient care may be altered by a physician`s point of view and subjective attitude towards dying patients. The goal is to hope for the best course of the illness or for the best quality of life for the longest possible time.
- **Do not Resuscitate (DNR**): Do-not-attempt-resuscitation (DNAR) and allow a natural death (AND) based on the practical reality that performing CPR is an attempt to save life rather than a guarantee. The National Health and Medical Research Council (2011:45) explain that some people believe that all attempts must be made to continue life since life is precious. Families want to feel that they have tried “everything” for the patients. If the heart of a patient stops, family members want to restart it with cardiopulmonary resuscitation (CRP) and defibrillation paddles. This is not an easy or even very successful endeavour in most cases. It may break some ribs and bruise some of the internal organs. If a heart does not restart quickly, brain damage occurs. This may lead to the loss of memory and paralysis (Mugnusson, 2009:113).
- **Decision-making**: The National Health and Medical Research Council (2011:45) indicates that decision making in terminal care is a demanding and stressful task for all involved and in any setting (hospitals, nursing homes, hospices or at home). Every patient has the right to know about the nature of his/her illness (patient autonomy) and physicians need to avoid giving false hope for cure. The WHO (2012:156) states that the palliative care team should not hide the truth or deliver the diagnosis abruptly, but rather break the news of the illness gently. The patient’s beliefs and values should be respected during the decisions making process in the case of an end of life issue, even if these differ from the family or the health care professional`s views.

The National Health and Medical Research Council (2011:46) states that decisions also need to respect cultural or religious beliefs, and the specific needs of groups such as people from culturally and linguistically diverse communities.

The WHO (2012: 158) supported the idea that patients and their families will need time to think about their goals and expectations in light of diagnosis and the expected disease course. Lasker (2013:27) explains that the last period of life is much different from the rest of life irreversible decay of bodily and mental capacities, pain and suffering, narrowing of the consciousness and awareness and lack of time. Many terminal palliative care patients like to avoid being subjected to unnecessary tests, hospitalisation, and intensive monitoring and resuscitation procedures. Advance directives may improperly influence health care providers to limit the care. Moreover, in some cultures and religions advance directives are forbidden (Khosla et al., 2012:241). Palliative care professionals may face challenges in treating end stages diseases in patients from these cultures.

1.11.4 Symptoms in end-of-life care

The following table indicates the types of symptoms common in end-of-life care.

Table 1.1: Common symptoms in end-of-life care

Common Symptoms in End-of-Life Care	
Symptom	**How to provide comfort**
Drowsiness	Plan visits and activities for times when the patient is most alert.
Becoming unresponsive	Many patients are still able to hear after they are no longer able to speak, so talk as if he or she can hear.
Confusion about time, place, or identity of loved ones	Speak calmly to help re-orient the patient. Gently remind the patient of the time, date, and people who are with them.
Loss of appetite, decreased need for food and fluids	Let the patient choose if and when to eat or drink. Ice chips, water, or juice may be refreshing if the patient can swallow. Keep the patient's mouth and lips moist with products such as glycerine swabs and lip balm.
Loss of bladder or bowel control	Keep the patient as clean, dry, and comfortable as possible. Place disposable pads on the bed beneath the patient and remove them when they become soiled.
Skin becoming cool to the touch	Warm the patient with blankets but avoid electric blankets or heating pads, as they can cause burns.
Laboured, irregular, shallow, or noisy breathing	Breathing may be easier if the patient's body is turned to the side and pillows are placed beneath the head and behind the back. A cool mist humidifier may also help.

According to Khosla et al. (2012:241), the above-mentioned common symptoms are presenting during the end-of-life stage.

The National Cancer Institute (2015:138) further explains that good management of symptoms in the terminal phase is one of the main concerns of patients and their families. The physical comfort of dying patients requires thorough assessment, excellent nursing care and careful prescribing.

1.11.5 Public policy on the role of the government in palliative care

Palliative care, whether for people with HIV, cancer or for others with terminal illnesses, is an essential part of any health care system. The WHO (2012:156) has identified three foundation measures to scaling up the provision of such care:

- **Development of a national policy**: Palliative care is not recognised in many government plans. For example, Uganda is the only country in Sub-Saharan Africa that has adopted WHO's foundation measures for establishing a palliative care service. While a handful of other countries in the region have some provision for palliative care, this is provided outside the government health service. Advocacy for provision of palliative care as part of the essential health service system by the government will be a move towards ensuring some budget allocation for the provision of care for those with chronic illnesses.
- **Training for health workers and public education**: Understanding of what palliative care is, and training to carry it out, is necessary for policy makers, health professionals and families. Such training needs to be linked to training in areas specific to chronic illnesses.
- **Pain control**: It is very crucial to consider pain control in terminal illnesses as it is done in cancer. Some studies have shown that pain is reported as a primary symptom by more than half of people with chronic illnesses. In many countries, this will require training and raising awareness among health professionals, and advocacy to change laws to make effective pain relief available.

1.12 TYPES OF TERMINAL ILLNESSES

The diseases and conditions in patients that are considered as terminal illnesses that require palliative care according to the Global Atlas of terminal illness are discussed below:

1.12.1 Cardiovascular disease

Cardiovascular diseases (CVD's) are a major cause of disability and premature death throughout the world, and contribute substantially to the escalating costs of health care. The underlying pathology is atherosclerosis, which develops over many years and is usually advanced by the time symptoms occur, generally in middle age. Acute coronary and cerebrovascular events frequently occur suddenly, and are often fatal before medical care can be given. Modification of risk factors has been shown to reduce mortality and morbidity in people with diagnosed or undiagnosed CVD's.

CVD's is the leading cause of death worldwide. The 2013 Global Burden of Disease Study estimated that almost 30% of all deaths worldwide were caused by CVD. However, recent evidence from Europe suggests that in some countries cancer has overtaken CVD as the leading cause of death. Over the last decade, survival from myocardial infarction (MI) has improved in England. The last decade has also seen changes in the number of prescriptions prescribed to treat various CVD conditions and the types of surgeries to treat MIs. The triggers for disturbances are varied and can primarily be related to the heart, like poor circulation of the coronary blood vessels, cardiac insufficiency, and defective heart valves, but also by high blood pressure, thyroid malfunction, mineral deficiency, toxins (alcohol, tobacco, drugs, and caffeine), infectious diseases, and more.

1.12.2 Chronic Renal Failure (CRF)

CRF also referred to as chronic renal disease (CRD), is a growing health care concern and a major public health burden in developed and developing countries. It is affecting more than 19 million people (adults and children) in the USA, and the prevalence of CRF is expected to double within 10 years especially among elderly people (Davison, 2007:17 and Nahas & Levin, 2009:77). Cameron (1996:29) added that many people who are dying of kidney failure are over the age of 70 years and a notable feature of kidney failure is that, the incidence rises steeply all the way from 15 to 90 years of age. Lewis and Noble (2013:17) noted that life expectancy is significantly reduced in patients with advanced CRF. The data show the median remaining life expectancy for dialysis patients to be 20 years for patients between the ages of 25 and 29 and 4 years for those aged over 75.

According to Nahas and Levin (2009:39-41) the main function of the kidneys is to filter waste and excess fluids from the blood, which are then excreted in the urine. Therefore, CRF means that the kidneys are no longer able to clean toxins and waste products from the blood and perform their functions to full capacity. As a result, this will lead to dangerous levels of fluid, electrolytes and wastes which will build up in the body. Furthermore, CRF will get worse over months or years and one may not notice any symptoms for some time until the functioning of the kidneys is significantly impaired. Moreover, delayed diagnosis and failure of institution measures to slow the progression of renal failure will result in end-stage renal disease (ESRD) and at this stage, kidneys are no longer able to remove enough waste and excess fluids from the body. Therefore, a dialysis or kidney transplant may be considered.

1.12.3 Multiple sclerosis

Multiple sclerosis (MS) commonly affects young adults and is the third leading cause of disability in the USA. It is estimated that 400. 000 Americans have this brain and spinal cord disorder which causes disruption of electrical messages from the brain to the peripheral nervous system (Nettina, 2014:524). Demyelination refers to the destruction of the myelin, the fatty and protein material that covers certain nerve fibres in the brain. This often results in disordered transmission of nerve impulses Nettina (2014:524).

The National MS Advisory Committee in the USA recognises four clinical forms of MS according to Nettina (2014:524). These are as follows:

- **Relapsing remitting**: clearly defined acute attacks evolve over days to weeks. Partial recovery of function occurs over weeks to months. Average frequency of attacks is once every 2 years and neurologic stability remains between attacks without disease progression.

- **Secondary progressive**: it begins as relapsing remitting(RR), but clinical course changes with increasing relapse rate, with a steady deterioration in neurological function unrelated to the original attack. About 50% of patients with RR will progress to secondary progressive (SP) within 10 years and 90% will progress within 25 years.
- **Primary progressive**: this is characterised by a steady progression of disability from onset without exacerbations and remissions. It is more prevalent among males and older persons. About 10 % of cases are diagnosed as primary progressive (PP).
- **Progressive relapsing**: this is the same as PP, except that patients experience acute exacerbations along with a steadily progressive course, but progressive relapsing is very rare.

1.12.4 Stroke

A stroke, also known as a cerebrovascular accident (CVA), occurs when the blood flow to the brain is interrupted. This could either happen when a blood vessel to the brain ruptures, causing bleeding, or becomes blocked by a blood clot. The affected brain cells then start to die because of a lack of oxygen and other nutrients. The severity of a stroke varies from a passing weakness or tingling in a limb to a profound paralysis, coma or death.

Premature deaths caused by heart and blood vessel diseases (CVD) in people of working age (35-64 years) are expected to increase by 41% between 2000 and 2030. The negative economic impact of this will be enormous. The major socioeconomic impact on individuals, families and communities in terms of health care costs, absenteeism and productivity has and become a major public health concern for the African region in particular.

Strokes are the third leading cause of death and the main cause of disability of adults in developed countries (Polivka, Rohan, Sevcik & Polivka, 2014:1). This is due to the fact that many people do not know that they are at risk of having a stroke until it actually happens to them. They normally do not see the symptoms of this disease beforehand. This is a global concern for many countries as a significant number of deaths are caused by this disease. In the USA about 500

000 people have a stroke each year. A third of these people die within the first few months after their diagnosis. About 10% of them will return to their previous level of functioning and 50% regain enough function to return home and carry on with limited assistance. Forty percent remain in institutions such as hospitals or rehabilitation facilities and require significant assistance (Brass, 2002:215).

1.12.5 Dementia

According to Clark (2008:504) dementia refers to a loss of intellectual function in multiple domains including memory, problem solving ability, judgment and others. It is a general term used to encompass cognitive deficits that include progressive memory loss and at least one other symptom such as aphasia (difficulty with written or verbal communication), apraxia (inability to correctly use objects), or agnosia (loss of comprehension of auditory, visual or tactile sensations).

1.12.6 Cervical cancer

Goosen and Klugman (1996:444) mention that when one is diagnosed with cervical cancer, it is natural to wonder what may have caused the disease as, doctors usually cannot explain why one woman develops cervical cancer and another does not. It is also mentioned that there are certain women with risk factors who are more likely than other women to develop cervical cancer. Friedland (2008:349) outlines the following as the risk factors that may lead to cervical cancer:

- Multiple sexual partners
- Starting sexual activity at a very young age
- Sexually transmitted diseases
- Smoking
- Possibly oral contraceptives

1.12.7 Bone marrow transplant

According to the National Health Institute, (2012:38) bone marrow is the spongy tissue inside the bones, such as the hip and thighbones. It contains immature cells, also referred to as stem cells. These stem cells can develop into red blood cells, which carry oxygen throughout the body, white blood cells, which fight infections, and platelets, which help the blood to clot. A bone marrow transplant is a procedure that replaces a person's faulty bone marrow stem cells. Doctors use these transplants to treat people with certain diseases, such as:

- Leukemia.
- Severe blood diseases such as thalassemia, aplastic anaemia, and sickle cell anaemia.
- Multiple myeloma.
- Certain immune deficiency diseases.

The National Health Institute (2012:39) further explains that before patients have a transplant, they need to get high doses of chemotherapy and possibly radiation. This destroys the faulty stem cells in the bone marrow. It also suppresses the body’s immune system so that it will not attack the new stem cells after the transplant. Bone marrow transplantation has serious risks and some. Complications can be life threatening.

1.12.8 Liver diseases

The National Institute for Diabetes and Kidney Diseases (2012:51) states that the liver performs many critical metabolic functions, including processing and distributing nutrients. Liver diseases can be caused by infection, such as hepatitis B and C, or by genetic mutations. Other liver diseases can be triggered by autoimmune reactions or drug toxicity. The rise in obesity in the USA has led to a rise in non-alcoholic fatty liver diseases. Many liver diseases place individuals at higher risk for developing liver cancer. The only current treatment for end-stage liver disease is a liver transplant, and the number of livers available from deceased donors is limited.

1.12.9 Pulmonary fibrosis

According to The American Thoracic Society (2010:40) pulmonary fibrosis is a lung condition characterised by extensive scarring of the lung. This usually includes extensive deposition of collagen and other components of the extracellular matrix, loss of normal lung architecture and change in the functions of the cells in the lung that lead to shortness of breath and ultimately, respiratory failure. Pulmonary fibrosis can be triggered or worsened by environmental or occupational exposure to tobacco smoke, infections, or drugs, or it can be secondary to autoimmune and inflammatory disorders. Idiopathic pulmonary fibrosis (IPF) is a disease in which progressive lung scarring occurs without an obvious cause.

IPF represents a significant health problem as it is estimated that close to 200,000 patients are affected in the US and over 5 million patients worldwide. The disease has a mortality rate of 50% 3-5 years after diagnosis, but the course is variable. Based on current guidelines the diagnosis of IPF requires a multidisciplinary approach and is usually based on the patient's history, pulmonary functions, high-resolution computed tomographic images and sometimes a lung biopsy.

1.12.10 Tuberculosis (TB)

Tuberculosis, commonly known as TB, is a contagious and an often severe airborne disease caused by a bacterial infection WHO (2012:103). TB typically affects the lungs, but it may also affect any other organ of the body. It is usually treated with a regimen of drugs taken for six months to two years, depending on the type of infection. The following are discussed as types of TB:

- **Multidrug-Resistant Tuberculosis (MDR TB)**: MDR TB is a form of drug-resistant TB in which TB bacteria can no longer be killed by the two(medication) best antibiotics, isoniazid (INH) and rifampin (RIF), commonly used to cure TB WHO (2012:103). As a result, this form of the disease is more difficult to treat than ordinary TB and requires up to two years of multidrug treatment.
- **Extensively Drug-Resistant Tuberculosis (XDR TB)**: According to WHO (2012:103) XDR TB is a less common form of multidrug-resistant TB in which TB bacteria have changed enough to circumvent the two best antibiotics, INH and RIF, as well as most of the alternative drugs used against MDR TB. These second-line drugs include any fluoroquinolone, and at least one of the other three injectable anti-TB drugs: amikacin, kanamycin, or capreomycin. As a result, XDR TB needs up to two years of extensive drug treatment and is the most challenging to treat

1.13 THE TIME LINE AND PHASES OF ILLNESS

McGoldrick, Carter and Preto (2011:352) and McDaniel, Doherrty and Hepworth (2014:250) explain the following major phases of dealing with life- threatening illnesses:

- **Prediagnostic phase**: McDaniel et al. (2014:257), state that this phase is associated with initial indicators of illness or disease and the tendency exists that, people often ignore these indicators by hoping that things will get better. Patients may try to minimise effective responses to the presence of the disease and, decide to investigate the significance thereof. Furthermore, they will seek out medical or professional sources for advice for investigate or diagnose the potential problem.
- **Acute phase**: This is the period in which one may try to understand the disease, maximise a healthy lifestyle, foster coping strength and limit weaknesses, develop strategies to deal with issues created by the disease, arrange for cure-oriented interventions, explore effects of the diagnosis, ventilate feelings and fear, and incorporate the reality of the diagnosis into one`s sense of past and future (Mcdaniel et al., 2014:257).
- **Crisis phase**: This phase includes any symptomatic period before the actual diagnosis and the initial period of readjustment and coping after the problem has been clarified through a diagnosis and initial treatment plan. During this period, there are a number of key tasks for terminally ill patients and their families. These include: learning to deal with pain, incapacitation, or other illness-related symptoms, as well as learning to deal with the hospital environment and any disease-related treatment procedures. The family needs to create a meaning for the illness event that maximises the preservation of a sense of mastery and competency grieve for the loss of the pre-illness.
- **Chronic phase**: According to McGoldrick et al. (2011:352), the chronic phase can be described as the time span between the initial diagnosis and readjustment period and the third phase in which issues of death and terminal illness predominate. McDaniel et al. (2014:258), indicate that it involves task like managing of symptoms and side effects, carrying out health regimens, preventing and managing health crises, managing stress, maximising social support minimising isolation and normalising life in the face of the disease.

McGoldrick et al. (2011:352), states that it is an era that can be marked by constancy, progression, or episodic change.

- **Recovery phase**: This phase still does not free a person from a need to cope, and recovery does not mean that one simply returns to the life led before. The recovery phase includes dealing with the aftereffects of the illness, anxieties about recurrence, reconstructing or reformulating one`s lifestyle, and redefining relationships with caregivers (McDaniel et al., 2014:259).
- **Terminal phase**: This is the time in which the individuals is faced with a new set of tasks such as dealing with on-going challenges arising from the disease, its side effects and treatments, dealing with caregivers and deciding to discontinue cure-oriented interventions or turning to interventions designed to minimised discomforting symptoms, preparing for death and saying good bye, preserving self-concept and appropriate social relationship and finding meaning in life and death (McDaniel et al., 2014:259).

1.14 THE FAMILY AS A CARE SYSTEM

Gallagher-Allred (2009:59) indicates that many patients are voicing their wish to die at home instead of in the hospital or in other health care institutions, which may place an unbearable pressure on some families, despite the bond that does exist between patients and their family members. The content of the bond that may exist within the family structure includes affection or love, caring, loyalty or commitment, responsibility or interdependence, and gratification (Gallagher-Allred, 2009:56). Despite the changes in family functions over the years, the family is still a primary institution in which each member practices behavior, develops attitudes, beliefs and values, and grows through fulfillment, failure, health and illness. The members of a family fulfill numerous functions (Peterson, 2009:34). The table below illustrates the most prominent functions of the family system.

1.14.1 Family functions

Table 1.2: Family functions

Family function	**Ways each function benefits**	
	Individual family members	**Society**
Membership & family formation	Provides a sense of belonging. Provides personal and social	Controls reproductive function. Assures continuation of the

Family function	**Ways each function benefits**	
	Individual family members	**Society**
	identity. Provides meaning and direction in life.	species.
Economic support	Provides for basic needs of food, shelter, and clothing and other resources to enhance human development.	Contributes to healthy development of members who contribute to society (and who need fewer public resources).
Nurturance, support and socialization	Provides for the physical, psychological, social and spiritual development of children and adults. Instills social values and norms.	Prepares and socializes children for productive adult roles. Supports adults in being productive members of society. Controls antisocial behavior and protects society form harm.
Protection of vulnerable members	Provides care and support for young, ill, disabled or otherwise vulnerable members	Minimises public responsibility for care of vulnerable, dependent individuals

According to Peterson (2009:35) the above functions are also of importance when a family has to take responsibility for its family members in the case of palliative care, as they can be regarded as disabled and vulnerable, and society then has less responsibility towards the terminally ill patient.

1.14.2 The family as caregiver for the terminally ill patient

In the context of a terminally ill patient, a caregiver generally refers to the person or persons in the home who are responsible for the primary care of the dying patient. In many families the caregiver is a patient’s wife, husband, mother, daughter, sister or other family members (Gallagher-Allred, 2009:57).

There is no doubt that taking care of a terminally ill family member, has a physical, psychological and financial impact on the family system. The physical demands on families are closely related to medical variables such as the stage of the disease, the level of symptomatology, the functional ability of the patient, and the side effect profile. The psychological impact of terminal illnesses like cancer can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, families may find that taking care of the terminally ill patient is time consuming and can lead to feelings of social isolation (Rocker, Puntillo, Azoulay & Nelson, 2010:152-153).

Fakhoury et al. (2007:161), stated that terminally ill patients spend in general as much as 90% of their time at home. Home is usually where people would like to be when ill and where they would like to die. The effect of care giving it range from negative responses such as anxiety, exhaustion, stress, strain, health related problems, financial hardship and role conflicts. The only positive responses are nevertheless also commonly which include the sense of challenge, providing family cohesiveness, and finding more purpose in life (Courtens, 2001:58-59).

The most difficult challenge that family members need to face is the moment when the patient enters the critical care stage and they realise that they have to face death and the implications that it will have for the family (Rocker et al., 2010:150-152). Shriner (2007:02) explains the following regarding the needs of terminally ill patients that the family system needs to take note of:

- **Physical care**: The biggest concern of dying persons is the control of acute and chronic physical pain. Other symptoms that may be as distressing or even more so than the physical pain include constipation, diarrhoea, nausea, vomiting, weakness, loss of appetite, shortness of breath, and dehydration (Shriner, 2007:02). Those who place a high value on self-image may be concerned about hair loss, dark circles around their eyes, and changes in their skin colour. Effective care must address all of the dying person’s physical symptoms. Physicians can help with pain management, while family members and other caregivers can be trained to provide physical care that will help them to be more comfortable. Corr et al. (2009:143), also stated that the physical task is to satisfy bodily needs and minimise physical distress, in ways that are consistent with other values.
- **Psychological care**: It is important to take note of what dying persons are feeling. They are likely to express negative feelings, including anger, sadness, anxiety, and fear. Corr et al. (2009:143), state that the main issue of psychological care is to maximise psychological security and autonomy and to realise that the patient’s emotions are real and they need to be identified and acknowledged. When family members are faced with these, many helpers

would experience discomfort and wonder what they should say and do. Unfortunately, there is no universal right thing to say or do. However, several things seem to be helpful such as speaking the truth and listening actively. A gentle touch is often experienced as psychologically healing.

- **Social care**: According to Corr et al. (2009:143), the social task focuses on sustaining and enhancing those interpersonal attachments that are significant to the person concerned, and sustaining selected interactions with social groups within the society. Dying persons want to maintain relationships with the special people in their lives. They may be concerned about their roles within the family, in the work force, and in the community. Many are concerned about who will care for and support the survivors, who will continue their special projects at work, and what will happen to their possessions. They may want to take care of some practical issues like arranging their funeral, telling their spouses how to do the chores, organising or passing down their material goods, and talking about the well-being of their loved ones in the future (Goldsteen et al., 2006:382). Social workers, family therapists, counsellors, and lawyers may also be of help in this regard.
- **Spiritual care**: Dying persons look for connection or continuity with some aspect of existence beyond the death of the body and search for some tangible evidence of continuity with on-going life after their own death (Staton, Shuy & Byock, 2001:239). The implied hope is that something they valued and cared about most in this world will continue to exist. Reassurance may come through passing their prized possessions on to loved ones, receiving assurance that their life’s work will continue, seeing qualities of themselves in their offspring, and connecting to a transcendent realm. According to Corr et al. (2009:143), spiritual care can be associated with addressing issues of meaningfulness and connectedness.

Families who are taking care of a terminally ill family member, also have certain needs. Gonda and Ruark (1984:210) list the following to take note of:

- **Education**: it includes learning as much as one desires about the terminal illness of a family member. It will include practical advice and training in such elementary skills as bathing, dressing, feeding, turning, and administering medication.

- **Respite care**: it includes periodic relief for the family from the watchful attention related to everyday living.
- **Emotional support**: usually includes the availability of bereavement support programs. Special attention needs to be given to the emotional support of the family during the arrangement of the funeral.

If the above needs have not been taken note of while caring for the terminally ill patient, the burden of taking care of such a family member, may become an unbearable task for the family system to achieve.

1.14.3 The role of the family caregiver

The role and demands of caregiving will depend on the setting of care such as caring for the patient at home versus in-patient units. Stajduhar and Cohen (2009:98) states that caring for the terminal ill patient at home can involve most immediate task may be about the most intimate of basic needs, such as physical aspects of care: giving baths, and helping them to eat, get dressed, use the bathroom, or even breathe. Whatever the specific tasks, hopefully it is a time of love and compassion and a time to resolve outstanding issues. Caregivers are also responsible for complex physical and medical care tasks including the assessment and management of symptoms, hygiene care, administration of medications, and consultation with health professionals (Hudson, 2009:88).

Furthermore, caregivers often have to provide comfort, emotional support, financial administration, patient advocacy, decision making, practical and social support, and the coordination of care (Stajduhar & Cohen, 2009:98).

1.15 IMPACT OF A TERMINAL ILLNESS ON THE CAREGIVING SYSTEM

According to several studies, it has been confirmed that caregivers' experiences high level of stress, such as the uncertainty of the correct treatment, lack of knowledge regarding patient care, difficulties in accessing services, financial burdens, and a general lack of support from the community (Kristjanson, 2009:139). Many caregivers must also manage secondary stressors resulting from emotional reactions from the patient and other family members, and from the financial impact of the sickness (Kalula & Petros, 2011:30).

According to the Institute of Medicine: Rare Diseases and Orphan Products (2010:26) caregivers in general face significant ethical challenges to their values and preferences for care at various transition points in the disease trajectory, for example, whether to participate in genetic testing, enrol in clinical trials, initiate mechanical ventilation, or withdraw therapies. Decisions of this nature, along with the overall strain of caring for a loved one, can lead to tension between the caregiver and the patient, as well as tensions in family relationships, as they struggle between hope and cure and the eventual fatality. NORD (2015:52) further explain that caregiver competence or perceived competence in caring for a loved one can affect caregiver quality of life. A caregiver’s perceived competence can be affected by many related variables, like family income, their loved one’s quality of life, and balancing the demands of other family members.

Furthermore, it has been well documented that caregivers must carry the dual responsibility of assisting the patient to prepare for death while coming to terms with their own grief and sense of impending loss (Candy et al., 2009:319). The impact of caregiving as categorised to different sections, can be summarised as follows:

- **Physical impact of caregiving**: the physical demands of caring for a patient with a terminal illness are often substantial and burdensome (Kristjanson, 2009:141). The American Society of Clinical Oncology (2013:09) states that caregiver burden is defined as the extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of caring (Kristjanson, 2009:141). This implicates that caregiving has a significant impact on caregivers' well-being, their needs are frequently considered secondary to those of the patient or are overlooked. Some research has suggested that caregivers of people with cancer may have more unmet care needs than patients (American Society of Clinical Oncology, 2013:09). Many caregivers report that the provision of personal hygiene and the administration of medication are particularly confronting (Kalula & Petros, 2011:31). A recent review by Stenberg et al. (2014:91), found that the most prevalent physical problems reported by caregivers are sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss. In an Australian study of caregivers, more than half reported that caregiving had directly affected their overall physical health, including tiredness and exhaustion (Stenberg et al., 2014:91).

- **Psychological impact of caregiving**: the physical demands of caregiving are the emotional and psychological demands. Caregivers report emotional distress coming from feelings of loneliness, fear, guilt, helplessness and lack of control over everyday life (Vanderwerker, Laff, Kadan-Lottick, McColl & Prigerson, 2005:68). Recently Price (2012:103) reported a significantly higher prevalence of borderline or clinical anxiety and depression among caregivers of women with invasive ovarian cancer compared with patients' rates and community norms. In studies looking at post-traumatic stress disorder (PTSD) in caregivers and partners of people with cancer, 4% of caregivers experienced PTSD, and one third of the partners of the caregivers’ experience different forms of traumatic symptoms. Despite the significant psychological impact of caring, caregivers might not seek required treatment. Vanderwerker et al. (2005:68), reports that almost half of cancer caregivers meet the diagnostic criteria for a psychiatric condition but would rather not seek treatment for it.
- **Impact on social activities and relationships**: social isolation is one of the most widely self-reported problems associated with family caregiving (Vanderwerker et al., 2005:69). These impacts resulted in loneliness, changes in family and other relationships, a sense of grief and loss, and limited time for personal relationships. Stenberg et al. (2014:118), state that even couples may struggle to manage the stress and challenges of cancer, as well as changes in their relationships brought on by the cancer diagnosis and such stress might lead to tension and conflict within the relationship. The American Society of Clinical Oncology (2013:09), suggests that early intervention and support may prevent the abuse of caregivers from occurring or reoccurring. Finally, while extended family members may be a major source of support for caregivers, it cannot be assumed that these interactions will always be positive. The blend of traditional roles with care responsibilities can result in changes to family dynamics, presenting new challenges for families and at times generating conflict.

- **Impact on financial and work status**: caregiving creates a financial burden for family members, both in outright expenses and in lost income and benefits (American Society of Clinical Oncology, 2013:11). Additional costs associated with care may include the purchase of equipment, bedding, home alterations, medical bills, rental equipment, respite, hygiene supplies and pharmaceuticals (Kristjanson, 2009:148). Caregiving also appears to reduce a person's chance of being employed, and many caregivers are unable to work, need to take leave without pay, have fewer work hours, are in lower paid jobs, or work from home to manage the caregiver demands (American Society of Clinical Oncology, 2013:11).

1.15.1 The positive impact of family caregiving

Ownsworth, Henderson & Chambers (2010:116) indicate that although caregivers often report experiences of shock, disbelief, anger, distress, fear, and depression in response to caring for terminal ill family members, they felt that caring for family members could also be an experience that can produce positive emotions. Ownsworth et al. (2010:121), state that according to an Australian study, 60% of caregivers were able to identify positive aspects of their roles as caregivers. When patients' symptoms were minor, the time together was described very emotively as “precious time,” which allowed the exploration of emotions and expression of love for the patient. Post bereavement caregivers in another Australian study reported the caregivers being proud, pleased, and satisfied that they had managed the caregiving role. Lambert, Harrison and Smith (2012:224) indicates that happiness over quality time spent with the patient, the ability to explore and resolve issues, feelings of value and self-worth have all been reported by caregivers. In addition, it has been suggested that caring for the patient may help caregivers to accept the death of the patient and work through their grief (Lambert et al., 2012:230).

1.16 HOME-BASED CARE SUPPORT SERVICES

Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore, and maintain a person’s maximum level of comfort, function and health, including care towards a dignified death (Borochowitz, 2011:42). The main aim of home-based care is to provide effective community-based care and support. Home care services can be classified into preventive, promote, therapeutic, rehabilitative, long-term maintenance, and palliative care categories. WHO (1999:97) states that community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life, and creates responsibilities.

HBC draws on the strengths of families and communities and its goal is to provide hope through good quality and appropriate care that helps patients and families maintain their livelihoods and the best possible quality of life (WHO, 1999:115). Various studies confirm that most people would rather be cared for at home, and that effective home care improves the quality of life of terminally ill patients and their family caregivers (WHO, 1999:173). For persons with terminal illnesses, a well-functioning HBC programme provides a continuum of care that extends from a healthcare facility to a home setting. To be effective, the HBC programme must be linked with and integrated into existing district healthcare delivery systems and plans. Effective HBC programmes are also results-based, and the inputs of families, communities, and healthcare systems are essential. Home-based care has become the alternative of choice in the wake of HIV/AIDS and other terminal illnesses. This is especially the case in Sub-Saharan Africa, the region with the highest prevalence rates of patients with terminal illnesses in the world (WHO, 2005:88 and UNAIDS, 2008a).

1.16.1 Effects of the CHBC programme on the health of terminally ill patients and their families

The WHO (1999:209) explains that a CHBC programme promotes caregiving to individuals in their natural environment, i.e. their home, by family members supported by skilled social welfare officers and communities, to meet spiritual, material and psychosocial needs, in which care the family caregiver plays a crucial role. The target group for this programme is any person with a terminal illness or full-blown AIDS, and chronically ill persons.

The WHO (1999:227) contends that between 70% and 90% of illness care takes place within the home. Research evidence demonstrates that most people would rather be cared for at home and that effective home care improves the quality of life of ill people and their family caregivers. HBC is one of the best ways for most people to receive quality care. According to Russell and Schneider (2010:276), home-based care has become a national policy priority in South Africa, as it helps those infected and affected with HIV and AIDS and other terminal illnesses to cope with the effects of their illnesses. Most importantly, it makes a significant contribution to relieving the burden of care resulting from HIV and AIDS on the health sector. In 2001, South Africa developed a national home-based care strategy, the Integrated Community-Based Home Care model, which resulted in the introduction of guidelines to operate home-based care programmes.

1.16.2 Support group services

Hornillos and Crespo (2012:126) indicate that a support group refers to a mutual aid group and is one of the most widely used and popular interventions with family caregiving. It has been identified as a basic form of psychosocial support for those families caring for terminally ill family members (Social Tract, 2010:51). A support group also creates an opportunity for the family caregivers to improve the condition of their environment, and provides them with the skills to manage a highly demanding situation and to relieve their emotional distress and maintain their quality of life. A support group provides a non-judgemental environment where family caregivers with similar experiences vent their feelings and discuss their problems, including financial and spiritual issues (Alzheimer’s Association, 2014:66).

A support group for family caregivers has been shown to have positive effects on the overall quality of life, psychosocial adjustment, physiological states, and even survival rates, hence it gives family caregivers an opportunity to share their feelings and concerns to overcome such feelings (Toseland & Rivas, 2012:199). Support groups have a variety of purposes and goals: to provide support, to educate, socialization, and self-help. Support groups enhance the family caregivers’ sense of self-esteem and assertiveness. It assists the group members to vent strong feelings such as anger, regret, and shame. Furthermore, a support group provides opportunities for family caregivers to learn powerful lessons about coping effectively with their family members with terminal illnesses. The majority of group members discover an improved sense of interpersonal confidence and self-worth from sharing their experiences and expertise with fellow group members (Hornillos & Crespo, 2012:137).

Social Tract (2010:83) explains that a support group offers benefits to the family caregivers and indicates that family caregivers gain experiences and learn from the different stories of other individuals and access more information. The group members also gain a better understanding of caring for family members with terminal illnesses and increase their knowledge on community resources and support services. Families benefit by dealing with their emotional issues, such as feelings about caregiving and their changed social condition, as well as health concerns, obsessive thoughts, fear, and grief. The support group also helps family caregivers to meet challenges, such as the lack of a support system and social isolation, and helps to reduce their stress and enhance their coping skills. This is supported by Mundell (2013:178), who states that family caregivers share their problems with other group members, therefore their burnout and emotional burdens are lessened.

1.17 THE IMPACT OF A TERMINAL ILLNESS ON CHILDREN

According to Obe, Hanks, Cherny and Calman (2004:801) there are at least three views on how children acquire fears and anxieties:

- The psychoanalytic view suggests that anxieties and fears in children are derivatives of other anxieties and fears that develop in early life, principally separation anxiety, fear of object loss, fear of castration, fear of abandonment, and fears of physical immobility and darkness.
- The cognitive view relates to children’s fears and anxieties about death to the stage of development and more concept of death. After the child develops the concept of the irreversibility of death, there will be a fear of its permanence.
- The social learning view puts forward the idea that children’s ideas and feelings are influenced by their experiences and by the observations of others. The fear of death and anxieties in children will be influenced by their parents, as well as siblings, peers, teachers, and relatives. Siblings and peers can provide ‘information’ about death that can be truly frightening. The media

(particularly television), children’s books, and fairy tales have also been noted to be significant influences (Obe et al., 2004:801).

1.17.1 Different types of losses in children

The following losses are of importance to take note of:

- **Developmental losses**: According to Bowlby (2008:173) developmental losses are common to all children and are negotiated more or less successfully depending on the unique circumstances of each child. Any distress associated with these losses will be short-lived for the majority of children, provided they have available to them the support of caring adults with whom they have a strong attachment. In the absence of such support, feelings of loss are less easily resolved and change is less readily accommodated.
- **Anticipated losses**: Anticipated loss depends on the developmental stage. Every time people make a change in their lives, an element of loss is involved, though the nature of the loss may not be obvious. The Dunblane Support Centre (2007:09) explains that where significant life changes are expected, children can share in events and take part in preparing themselves for the future. By allowing children to share in events, whether it is moving house or the terminal illness of a relative, children need some time to work through the grieving process (Jack, Munro & Oliver, 2009:110). Preparation for loss provides children with opportunities to develop helpful coping strategies for when the loss actually occurs (Bowlby, 2006:176).
- **Unexpected losses**: According to the Dunblane Support Centre (2007:12), sudden and unexpected losses are much more difficult to children to cope with. They are often associated with crisis and traumatic events where there is a perceived threat to the child’s sense of security or personal safety. Hallam and Vine (2010:336), indicate that in these situations a child may be thrown into a frightening world of grieving with few strategies to cope and a limited vocabulary to articulate feelings of loss. To make matters worse, they may find their primary carers emotionally unavailable to them because many adults also have difficulty in coping with more traumatic events to come.

1.17.2 The needs of grieving children

According to Worden (1991:94), there is an important distinction between grief and mourning, a distinction that is vital to recognise when working with bereaved children. Worden (1991:94) describes grief as the internal meaning given to the experience of bereavement, whilst mourning means taking the internal experience of grief and expressing it outside oneself (Wolfelt, 1996:15).

The Dunblane Support Centre (2007:12) further elaborates that the common grief needs are: reassurance, open and honest communication, recognition of grief, sharing grief, to say goodbye and, a break in grieving. Dyregrov (2008:169) indicates that reassurance is vital to children who have experienced loss and they will need reassurance about the basics of life, such as where they will live and who will take care of them. Where there has been a death through illness, children need to know that they will not die from catching the disease. When children harbour guilt feelings linked to the death of a loved one, they will need reassurance that their feelings did not cause the death. In all cases of loss, children need the reassurance provided by being in a stable environment. Worden (1991:107) explains that the need for open and honest communication is linked to the need for reassurance, and Dyregrov (2008:188) states that loss and death can be explained truthfully and gently by giving age appropriate explanations and by using age appropriate language. To do otherwise usually confuses children, and may deny them the opportunity of validating their own feelings. By acknowledging, that death is unfair and makes people very sad, adults can help children acknowledge their own feelings.

Sharing grief may mean that children have to talk about their losses (Worden, 1991:107). Not all children can express their feelings in words and for very young children it might be unrealistic to expect them to do so. Some children may have genuine difficulty in expressing their feelings in words or they may wish to protect the adults around them from the pain of the loss. Children, especially young children, express their feelings through their play and behaviours (Dyregrov, 2008:197). Many children can more readily express their feelings through artwork, drama or a variety of physical activities. Significant adults, such as parents, carers and teachers, can create a reassuring environment where it is safe to talk or can create opportunities for children to express themselves in non-verbal ways. According to the Dunblane Support Centre (2007:39), the minority of children may become stuck in grief and may require some special help to work through their feelings. Providing children with opportunities to say goodbye in situations of anticipated loss gives them the time to work through parting and helps them accept the loss. Yet, it can be an opportunity for children to say the things they want to say, to plan ways of remembering and to begin grieving (Worden, 1991:115). Adults can help by listening to children and helping them find appropriate ways of saying goodbye to a loved one, perhaps through a letter or poem, or a symbolic act.

All children need and deserve a break from grief because it can be a long and tiring process (Dunblane Support Centre, 2007:41). This applies to all children who have experienced a major loss, not just the bereaved. They may feel they are betraying the person they were mourning. A way of helping children overcome such concerns is to help them realise that is acceptable to get rid of sad feelings and to make room for happy ones.

1.17.3 Immediate reaction of children

According to McGoldrick et al. (2011:286), the reaction of children to death depend on their stage of emotional and cognitive development. In dealing with children, it is crucial for adults to recognise the limitations of the child's ability to understand what is happening (McGoldrick et al., 2011:286). In situations when a death is anticipated, children's reactions will depend on the extent to which they have been prepared for the death. If they have time to prepare mentally for the death and have had the opportunity to say farewell, then they are likely to experience a less intense reaction than when the death is sudden (Jack et al., 2009:118).

Dyregrov (1991:212) and Hallan and Vine (2010:348) describes the most common immediate reactions as shock, disbelief, dismay and apathy. The Dunblane Support Centre (2007:12) further explains that children often respond with disbelief when they learn of the death of someone close to them. Sense of emotional shock they feel is made up of a variety of emotions including numbness, denial and disbelief. Adults can misunderstand such reactions believing that they reveal an apparent lack of feeling or indifference to the death (Hallan & Vine, 2010:348). These reactions need to be understood for what they are, namely: a protective mechanism intended to enable the child to cope with the loss at their own pace and in their own time. Continuing with ordinary, usual activities is often the child's attempt to make their world feel safe and secure again.

1.17.4 Grief reactions of children

Following immediate grief reactions, children may display a whole range of grief responses. Worden (1991:116) and Dyregrov (2008:215) explain some of the most common physical, emotional and behavioural responses as follows:

- **Physical**: tiredness disturbed sleeping pattern, lack of appetite or excessive appetite, tightness in the throat, headaches, stomach pain, and difficulty to concentrate. The aches and pains that children may complain of following bereavement, are appropriate reactions and are usually temporary of nature. Adults need to reassure the grieving child that it is temporary in nature and in doing so, lessen the child's concern about his or her personal wellbeing. They also need to recognise that children move in and out of grief.
- **Emotional**: These emotions refer to anxiety, fear, guilt, shame, sadness, longing, anger, and relief. Anxiety and fear are very common reactions in children following the death of a loved one and these feelings can take many forms. Young children may become more clingy and demanding and they may react adversely to separations. Older children often express their fears and anxieties less directly by seeking reassurance about practical aspects of daily living following the bereavement.
- **Behavioural**: Behaviours such as acting out behaviour, regression, social isolation, pseudo-maturity, disorganisation, and problems at school may occur. Acting out behaviour in bereaved children is often an indirect cry for help. The feelings underlying such behaviour appears to be anger and, depending on the developmental level of the child, can be expressed through temper tantrums, defiance, aggression towards others, or under-achievement at school. Bereaved children may also act out because they feel insecure, fear abandonment, seek punishment for imagined misdeeds against the deceased

or seek rejection as a way of protecting themselves against future losses. For the adults faced with the daunting task of dealing with acting out behaviour, it is important to understand the underlying purpose of the behaviour and essential that they set appropriate limits.

1.18 THE FEARS OF FAMILIES AND TERMINALLY ILL PATIENTS

In a study by Gallagher-Allred (2009:59), it is indicated that many patients are voicing their wish to die at home instead of in the hospital or in other health care institutions. Patients and family members often experience the fear of performing the task of taking care of terminally ill family members due to the uncertainty of what the future will hold and what to do when an unmanageable crisis develops and they are unable to obtain support.

Family members are often unable to distinguish a serious problem from a trivial one and typically interpret small or large changes in the patients. They fear not knowing what to do in emergencies, or at the time of death. Furthermore, family members are often concerned about the effect of taking care of terminally ill patients on other family members.

1.19 GRIEF IN TERMINALLY ILL PATIENTS

According to Corr et al. (2009:245), grief is an expected reaction in patients and caregivers facing a life-threatening illness and needs to be acknowledged and expressed. In dealing with patients who have a life-threatening disease, grief work should be encouraged as patients who express their grief early in the disease process, are more likely to accept the fact that they may die soon.

1.19.1 Complicated grief

Corr et al. (2009:245), state that complicated grief may appear as a complete absence of grief and mourning, an on-going inability to experience normal grief reactions, delayed grief, conflicted grief, or chronic grief. Factors that contribute to the chance that one may experience complicated grief include the suddenness of the death, the gender of the person in mourning, and the relationship to the deceased, for example: an intense, extremely close, or very contradictory relationship. Grief reactions that may turn into feelings of depression, should be treated with both drug and psychological therapy (Corr et al., 2009:245).

- **Chronic grief reactions**: these type of reaction are prolonged in duration and do not lead to an appropriate outcome, as when an individual becomes aware that they are not making progress in getting back into living again (Corr et al., 2009:245).
- **Delayed grief reactions**: this reaction prevents the child to be unable to act in a natural way. In most cases they suppressed or postponed, not surfacing again until later, when it most often appears as an excessive reaction to a subsequent loss or other triggering events (Corr et al., 2009:245).
- **Exaggerated grief reactions**: excessive and disabling reactions in ways that may lead to the development of a phobia or irritable fear to physical or psychiatric symptoms and maladaptive behaviour (Corr et al., 2009:245).
- **Masked grief reactions**: individuals experience symptoms or behaviours that cause them difficulty, include the complete absence of grief, but which they do not recognise as related to the loss (Corr et al., 2009:245).

1.19.2 Anticipatory grief and mourning

According to Corr et al. (2009:240), anticipatory grief and mourning is a process that encompasses grief and mourning, coping, interaction, psychosocial reorganisation, planning, balancing conflicting demands, and facilitating an appropriate death. Grief and mourning are experienced not only by the survivors, but also by the dying person. Persons diagnosed with a terminal illness may grieve over the past, present, and future losses they are forced to endure, along with the final loss of self. This time create an opportunity for the dying person to plan the future cooperatively with the survivors so that unilateral plans will not be perceived as betrayals after death (Corr et al., 2009:240).

Anticipatory grief and mourning can play an important part in the dying process of the terminally ill person and the bereavement experience of the survivor (Corr et al., 2009:242). The time before a death can be used effectively by the dying person and significant others to complete unfinished business. When unfinished business is expressed, the bereaved more than likely will not have to spend time in grief counselling dealing with regrets over things that were not said when there was an opportunity. A person who has shared their thoughts and plans with the dying person, who has begun to anticipate life without this person, and who has made adequate preparation for managing affairs, is in a better position to cope with bereavement than a person who has denied the illness until it was too late to prepare for the death (Corr et al., 2009:242).

Anticipatory grief does not mean that caregivers and significant others withdraw from the dying person, but rather that they begin to learn to accustom themselves to a life without the presence of the dying person. It allows for survivors to plan for the future and to gradually absorb the reality of the impending death, and rehearse the death and its consequences (Corr et al., 2009:242).

1.19.3 The stages of death

Swiss psychologist, Elizabeth Kübler-Ross describes the stages experienced by patients about to die, from when they receive the malignant diagnosis to the time when they accept it. People who are dying go through specific stages in this grieving process namely: from denial to anger, from negotiation to depression, and finally acceptance (Sorensen & Luckmann, 1998:1859).

Communication occurs in grief-stricken people, through their emotions, actions, and words. Kübler-Ross and Ross Medical Association (1981:122) place much emphasis on communication, as she indicates that when people are approaching death and going through the five stages of the grieving model, they wanted to review their lives, the illness and imminent death. The author of this model and her thoughts are influential to health care providers, as it provides guidance to approaching and interacting with people experiencing grief. The five stages of the grieving process are as follows:

- **Denial and isolation**: Chapman (2011:76) states that denial is a conscious or unconscious refusal to accept facts, information, and reality relating to the situation concerned. It is a defence mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. Death of course is not particularly easy to avoid or evade indefinitely. Gonda and Ruark (1984:33) explain that this can be so pronounced that patients or family members simply do not recall important statements that have been made to them. The first reaction to learning of the terminal illness or death of a loved one is to deny the reality of the situation. It is an appropriate reaction to rationalise overwhelming emotions as it is a defence mechanism that buffers the immediate shock. This carries people through the first wave of pain. In essence, it serves as protection for the person who is constantly confronted with a painful reality. During the stage of denial, health care must be provided to support the individual to come out of the denial phase.

- **Anger**: very often anger is expressed more directly towards family members and care providers (Kubler-Ross, 1987:281). Religious beliefs can be another area to which the dying directs their anger and frustration. During this stage, the nurse might see an individual who was normally kind, cooperative and polite treat his wife with cruel words. The wife can feel very confused at this sudden explosion of anger. Anger can also be expressed against God or the priest (especially people who have lived a religious life, may feel a deep anger because God allowed this to happen to them). The dying must be able to express their anger without running the risk of losing those who are important to them. The professional person needs to ensure that patients get an opportunity to express their anger towards the family members (Sorenson & Luckmann, 1998:1859).

  Chapman (2011:76) explains that anger can manifest in different ways. People who have to deal with emotional upset can often be angry with themselves, or with others, especially those close to them. Knowing this helps the patients to keep detached and non-judgemental when experiencing the anger of someone who is very upset. The intense emotion is deflected from their vulnerable core, redirected and expressed instead as anger. The anger may be aimed at inanimate objects, complete strangers, friends or family. Gonda and Ruark (1984:33) stated that anger is almost constantly present on some level in both the dying and their loved ones, and it may show itself in many contexts and in unexpected ways. The following may be some of the ways:

- **Bargaining or Negotiating:** This is a way of trying to postpone the inevitable. Negotiation can be done in various forms such as repeatedly asking for medical treatment. The patients can look for a doctor or a treatment, which, in essence, enables them to better negotiate life. They can negotiate with care providers with regard to controlling the timing of medication or the promise to cooperate in the type of treatment if they are allowed to go home for the weekend. This can be noticed in individuals who ask God to have more time in life. According to Kübler- Ross (in Sorensen & Luckmann, 1998:1859-1860) they reach the point where they understand that the unavoidable cannot be postponed, which takes them to the next phase, namely depression.

Chapman (2011:78) indicates that traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever religion the person believes in. Bargaining rarely provides a sustainable solution, especially if it is a matter of life or death. When bargaining does occur, it often constitutes an understandable attempt by those who feel overwhelmed and helpless to establish some sense of control over their own destiny (Gonda & Ruark, 1984:33). The following reaction to feelings of helplessness and vulnerability of the patient is often a need to regain control:

- If only we had sought medical attention sooner.
- If only we got a second opinion from another doctor.
- If only we had tried to be a better person.

Secretly, patients may make a deal with God or another higher power in an attempt to postpone the inevitable. This is a weaker line of defence to protect them from the painful reality.

- **Depression**: Depression is a realistic period of suffering, due to everything that is almost lost and also for the losses that have, in fact, already occurred. During this period, individuals have a tendency to give up on the world. Their appetite tends to reduce and there can be changes in sleeping patterns. It is not uncommon to see them lying down or sitting with their backs to the door, avoiding family members and care providers and distancing themselves from them. The professional person can assist patients going through that period, by providing physical care with kindness and observing them frequently without demanding a verbal answer in exchange (Sorensen & Luckmann, 1998:1860).

Chapman (2011:81) states that depression can also be referred to as preparatory grieving. In a way it's the dress rehearsal or practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment as it is acceptable to feel sadness and regret, fear and uncertainty. It also shows that the person has at least begun to accept reality. Two types of depression are associated with mourning. The first one is a reaction to practical implications relating to the loss, sadness and regret. This phase may be eased by simple clarification and reassurance. The second type of depression is more subtle and, in a sense, perhaps more private. It is a silent preparation to separate and to bid loved one`s farewell.

- **Acceptance**: Although it varies according to the person`s situation, Chapman (2011:82) describes this stage as the period in which some form of emotional detachment and objectivity takes place. People that are dying, can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief. Reaching this stage of mourning is a gift not afforded to everyone. Death may be sudden and unexpected or people may never see beyond their anger or denial. It is not necessarily a mark of bravery to resist the inevitable and to deny oneself the opportunity to make peace with the reality. This phase is often characterised by withdrawal and calmness.

During this period, the patients become aware and fully accept the implications of their prognosis. There is a feeling of satisfaction towards the life lived and incomplete issues have been finalised. Furthermore, this is the time to say the final goodbyes. Acceptance is for example illustrated by the individual by accepting that the time remaining is short, making the decision to leave the hospital to spend time at home in peace and leaving a legacy of warmth and peace behind for their beloved ones (Sorensen & Luckmann, 1998:1860).

Terminal patients must be given the opportunity to speak about death, so that they can reach the phase of acceptance. As palliative care is the active holistic care of patients with an advanced progressive illness, nurses should take care and allow the patient to verbalise and interact about his or her feelings, fears and anxieties.

Coping with loss is ultimately a deeply personal and singular experience. Nobody can help a person to go through it more easily or to understand all the emotions that he/she will experience. The best thing to do is to allow oneself to experience the grief. Resisting it will only prolong the natural process of healing (Kübler-Ross & Ross Medical Association, 1981).

Kubler-Ross (1969:106), stated that people who are dying also have great longings for communication about questions such as "Why me?" Dying persons grieve the many losses they have had to endure, including the loss of security, independence, and a future. Caregivers, friends, and significant others may not be able to discuss these issues, denying the dying person an opportunity to discuss shared fears, hopes, needs, and unfinished business.

1.20 COPING STRATEGIES OF THE TERMINAL ILL PATIENT

Kovac, Patel, Peterson and Kimmel (2012:21) state that coping is the constellation of many acts rather a single act, is constantly changing and is highly individualized. Coping mechanism are learned and developed over time for human beings to use to manage, tolerate and to reduce stress. Everyone has a variety of coping mechanism developed through life experiences, although each individual relies on a predominant coping style as a way to reduce anxiety and to restore equilibrium when confronted with a stressful situation.

Coping strategies are manifesting through behaviour, and individuals will cope with the illness in different ways. The social environment in which the individuals find themselves can facilitate or discourage effective coping (Kovac et al., 2012:21). In general, an environment that helps individuals gain a sense of control through active participation in decision-making and taking responsibility for their own destiny as much as possible best equips them to cope effectively with terminal illnesses.

The following are some of the coping strategies:

- **Denial**: Kovac et al. (2012:24), state that a diagnosis of terminal illness and the associated implications can be devastating and provoke anxiety. Therefore, denial is the coping strategy an individual uses to negate the reality of a situation. In the case of terminal illness, individuals may deny that they have the condition by avoiding recommended treatment or by denying the implication of the condition. Kovac et al. (2012:24), state that in the early stage of adjustment, denial may be beneficial in that it enables the individual to adjust to the reality of the situation at their own pace, preventing excessive anxiety. Denial of the terminal illness can have far-reaching effects on others as well if, by denying the condition, the affected patient places others at risk.

- **Regression**: Kovac et al. (2012:36), indicate that in regression, a patient reverts to an earlier stage of development, so that they become more dependent, behave more passively, or exhibit more emotionally than would normally be expected at their development al level.
- **Compensation**: the patient using the compensation coping strategy learns to counteract limitations in one area by becoming stronger or more proficient in another area (Kovac et al., 2012:36). When function is lost in one area, the patient may find a way to excel in another sphere. Compensatory behaviour is generally highly constructive when new behaviour are directed towards positive goal and outcomes (Kovac et al., 2012:36).
- **Rationalisation**: rationalisation enables a patient to create acceptable reasons for their behaviour or to excuse themselves for not reaching goals or not accomplishing tasks. According to Kovac et al. (2012:38), rationalisation can soften the disappointment of dreams unrealised or goals not reached, it can also produce negative effects if it becomes barriers to adjustment, prevents individuals from reaching their full potential or interferes with effective management of the medical condition itself.
- **Diversion of feelings**: Kovac et al. (2012:41), explain that constructive of all coping strategies can be the diversion of unacceptable feelings or ideas into socially acceptable behaviour. Individuals with a terminal illness may have particularly strong feelings of anger or hostility about their diagnosis or the circumstances surrounding their condition (Kovac et al., 2012:39). If their emotional energy can be redefined and diverted into positive activity, the results can be beneficial, making virtue out of necessity and transforming deficit into gain. As with all coping strategies, diversion of feelings can have

negative effects if feelings of anger or hostility are channelled into negative behaviours or socially unacceptable activities (Kovac et al., 2012:42).

1.21 EMOTIONAL REACTIONS OF THE TERMINALLY ILL PATIENT

According to Livneh and Wilson (2011:198), terminal ill patients view their condition as a challenge or an enemy to be fought, a punishment, a sign of weakness, a relief, a strategy for gaining attention, an irreparable loss, or an uplifting spiritual experience (Kovac et al., 2012:46). Although the emotional reaction of terminal ill patients vary in both type and intensity, the following reaction are common to take note off:

- **Grief**: Livneh and Wilson (2011:199) describe grief as a small reaction to loss. Terminally ill patients may experience loss of body parts, functions, role and social status. Although the grieving and progression through stages of grief may vary from patient to patient, a common initial reaction during terminal illness is shock, disbelief, numbness with the diagnosis or denying/disputing its seriousness. Kovac et al*.* (2012:46), state that after repeated confrontation with elements of loss, normal adaptation results in a gradual change in emphasis and focus that enables a patient to accept loss emotionally and to make adjustments and adaptations that are necessary to re-establish their place within the everyday world.
- **Fear and Anxiety**: Patients normally become anxious when confronted with a threat. The presence of a terminal illness can pose a threat because of the potential loss of function, loss of love, loss of independence and loss of financial security. Threat causes anxiety and some patients fear the unknown or unpredictability of the condition, which on the other hand provokes anxiety (Livneh & Wilson, 2011:199). When conditions are life threatening, fear and anxiety may be associated not only with loss of function, but also with loss of life. Fear and anxiety associated with terminal illness can place a patient in a state of panic, rendering them psychologically immobile and unable to act (Livneh & Wilson, 2011:199). It is important to note that the fear experience by patients may have both rational and irrational aspects. Fear and anxiety are often future oriented, having to do with perceptions of what could occur rather

than based on what is actually known in the present (Livneh & Wilson, 2011:199).

- **Anger**: Terminally ill patients may experience anger at themselves or others for perceived injustices or losses associated with their conditions (Kovac et al., 2012:48). They may believe that their terminal illness was caused by negligence or that their condition was avoidable. If they perceive themselves as victims, their anger may be directed towards the persons or circumstances they blame for the condition, but if they believe that their own actions were partly to blame for the terminal illness, the anger may be directed inwards (Livneh & Wilson, 2011:201). Anger can also be the result of frustration and patients may vent their frustration and anger by displacing hostility towards others even when those parties have no relationship to the development of the terminal illness and no influence over its outcome. Anger may also be the realisation of the seriousness of the situation and associated feelings of helplessness. At times anger may not be openly expressed but rather hidden in quarrelling, arguing, complaining, or being excessively demanding, in an attempt to gain control (Livneh & Wilson, 2011:201). Helping patients to express anger in appropriate ways and enabling them to regain a sense of control over their situation can help to resolve anger.
- **Depression**: The reality is that the terminally ill patient may experience feelings of depression, helplessness and hopelessness, apathy, dejection, and discouragement (Livneh & Wilson, 2011:201). Signs of depression include sleep disturbances, change in appetite, difficulty in concentration, and withdrawal from activity. The extent to which depression is experienced varies from patient to patient. Prolonged or unresolved depression can even result in self-destructive behaviours such as substance abuse or suicidal attempts.
- **Guilt**: According to Livneh and Wilson (2011:202), guilt can be described as self-criticism or blame. Patients or family members may experience guilt if they believe they contributed to or in some way caused their illness. A good example may be that of a patient who develop lung cancer or emphysema after years of using tobacco or those who experienced spinal cord injuries owing to an accident that occurred because they were driving while intoxicated (Kovac et al., 2012:50).

1.22 PHASES OF THE DYING PROCESS

Weisman (1991:390) describes the following reactions demonstrated during the process of dying which are closely tied to a course of the terminal illness:

- **Phase one**: **Existential plight**. It refers to the initial shock of abrupt confrontation with incontrovertible evidence of one`s own vulnerability and mortality. During this early period, the patient and family members are likely to exhibit signs of numbness and shock, as well as a sense of being overwhelmed.
- **Phase two**: **Mitigation and accommodation**. This reaction often follows initial treatment, when the possibility of relapse or recurrence remains very real. Focus among patients and families tend to shift towards achieving a satisfactory balance between the new role as a potentially dying patient. An accommodation is often made between the daunting reality of the disease and the requirement of customary occupation and concern. The main emphasis during this period seems to be directed towards the achievement of premorbid levels of functions. The battle against invalidism becomes primary, and the maintenance of even the most trivial of abilities can become critical to psychological well-being. The role of denial in this dynamic is apparent, although not necessarily problematic.
- **Phase three**: **Decline and deterioration**. This occurs as the illness advances, as recurrences accumulate and treatment results in shorter periods of relative freedom from symptoms, and as energy for living begins to wane. This period of a terminal illness may be the most difficult for many patients and families faced with the seemingly inexorable progress of disease and disability. This is when the signs of advancing illness become unavoidable even to the most denying of observers. The prospect of death assumes a new concreteness, and everyone involved with the reality of death may have to struggle to maintain hope.
- **Phase four**: **Preterminality and terminality**. In this phase, the responses to treatment become minimal and everyone involved begins to realise that the focus must shift to palliation of symptoms and assurance of as much comfort as possible. Patients and families may become acutely aware of the limitation of the time they have left together and consequently they may appropriate alter

their goals to be much more limited than those previous (Gonda & Ruark, 1984:35).

1.23 THE ROLE OF THE SOCIAL WORKER IN THE FIELD OF HOME CARE OF TERMINALLY ILL PATIENTS AND THEIR FAMILY MEMBERS

1.23.1 Introduction

According to Bern-Klug, Gessert and Forbes (2009:81), clinical social workers rendering counselling services in end of life-practices must work with patients who are dying and their families on issues related to “value clarification, emotional assessment, crisis intervention, goal setting, decision making, dealing with transition and loss, active pursuit of interpersonal growth, and the pursuit of peace of mind.”

Counselling is thus useful in understanding the context of the dying patient, their background, and their networks and relationships. Singer and Bowman (2009:63) add that, the practice of counselling in end-of-life care, offers counsellors opportunities to identify the stressors and design coping strategies for patients and their carers. The roles of the social worker are as follows:

- Social workers help to gauge the extent to which the nursing home’s social environment is supportive of the quality of life for residents, family, and staff and are empowered to exercise leadership to enhance the setting, as appropriate according to the needs and desires of residents, family, and staff.
- Social workers are part of a team that anticipates and addresses family members’ concerns and evaluates interventions for effectiveness.
- Social workers are part of a team that anticipates and addresses resident psychosocial concerns including those related to declining health status and evaluates interventions for effectiveness.
- Social workers connect residents and family members with community resources and assist residents in moving out of the nursing home if that is their wish.
- Social workers are able and willing to train fellow staff members in recognising and addressing resident and family psychosocial challenges.
- Social workers identify and honour their own psychosocial needs.

- Social workers have the skills and willingness to advocate for improved palliative care at the individual, facility, community, and public policy levels.

According to Bern-Klug, Gessert and Forbes (2009:82), the following figure indicate the role of the social worker in long-term care settings.

1.23.2 Indicators on the role of the social worker

Figure 1.1 Role of social worker

(Source: Bern-Klug, Gessert and Forbes, 2009:82).

1.23.3 Multicultural issues in terminal illness

According to, Giger, Davidhizar and Fordham, (2006:231) the adjustment and adaptation to terminal illness are also related to a variety of cultural aspects, including race, gender, ethnicity, spiritual or religious beliefs, and sexual orientation. The concepts about causes of terminal illness and reasons for various health conditions, values, and accepted ways of managing a condition are all cultural variables that determine attitude, adjustment, expectation and outcomes related to terminal illness.

1.23.4 Cultural factors to consider during terminal illness at the end of life

Working within the cultural context of the patient and family is an essential underpinning of end-of-life care. Cultural influences can significantly impact the patient's reaction to the dying process and the decisions the patient and family make (Giger et al., 2006:231 & Searight & Gafford, 2005a:335). The factors to be considered are as follows:

- **Death as a taboo subject**: In some cultures, talking openly about death and dying is not acceptable because it is considered disrespectful, bad luck, or as causing loss of hope (Giger et al., 2006:231). Many cultures actively protect dying family members from knowing their prognosis (Carteret, 2012:73).
- **Collective decision-making**: In collective decision-making, the family decisions will be family oriented. In these circumstances, it is important to understand and respect that the power of collectivism is more important than an individual (Huff & Kline, 2007:259).
- **Perception of pain and request for pain relief**: Culture can affect a person's response to pain, both in the meaning and in expression of pain. Pain may be seen as something positive, a sign that the body is fighting towards recovery as a test of one's faith through suffering or even as a punishment (Giger et al., 2006:238 & Shavers, 2010:98). Therefore, for some individuals, asking for pain medication may be considered a sign of weakness.
- **Role of religion and faith**: For many ethnically diverse cultures, the approach to health and illness is through the interconnection of mind, body and spirit with nature or the environment. Faith and spirituality can play a significant role in the perception and response to the dying process (Giger et al., 2006:238 & Shavers, 2010:98).
- **Use of traditional healing**: The use of Western medicine is generally acceptable to ethnically diverse patients in the care of terminal illness, although the level of acceptance depends on a number of factors (Giger et al., 2006:240 & Shavers, 2010:103). Alternative practices may be used simultaneously with Western medicine because of the perceived or real effectiveness of the treatments as experienced by the patient. Symptoms often experienced as a result of the disease and dying process include pain, nausea and vomiting, breathing difficulties, skin wounds, bowel and bladder problems, anxiety and depression, and sleep disturbances. To address these symptoms, patients may seek the care of spiritual healers and the use of alternative practices.

1.24 TASK-BASED MODEL FOR COPING WITH DYING

Corr et al. (2009:142), states that there are four primary areas of task work in coping with dying. These tasks are as follows:

- **Physical tasks**: Physical tasks are associated with bodily needs and physical distress that is coping with such matters as pain, nausea and constipation and satisfying such needs as hydration and nutrition. As Maslow (1971:104), argued satisfaction of fundamental bodily needs is usually the indispensable foundation on which the work of meeting other needs can be built. Physical distress cries out for relief both for its own sake and in order that the rest of life can be appreciated and lived well. For example, individuals experiencing intense pain, severe nausea, or active vomiting are unlikely to be capable of rich psychosocial or spiritual interaction at the same time (Corr et al., 2009:143).
- **Psychological tasks**: The majority of people who are coping with dying seek a sense of security, autonomy and richness. They need security even in the situation that in many ways may not be safe. For example, if they are dependent on others to provide needed services, they may need to be assured that those providers are reliable (Corr et al., 2009:143). Most individuals who are coping with dying wish to retain their autonomy, as far as that is possible. Autonomy means the ability to govern or to be in charge of one’s own life. For many people achieving sense of security and autonomy contributes to a psychological richness in living. Those who are near the end of life still appreciate opportunities for a regular shave and haircut, to have their hair washed and set and to dress comfortably. Some dying persons may find it important to their psychological well-being to have a taste of their favourite food or to continue a lifelong habit of drinking a glass of wine with meals. The issue involved here refers to personal dignity and quality of living (Corr et al., 2009:143).
- **Social tasks**: One of the social tasks is to do with sustaining and enhancing the interpersonal attachments valued by a coping person (Corr et al., 2009:144). Dying individuals often narrow the scope of their interests, they increasingly focus on issues and attachments that involves a progressively smaller number of individuals that are now perceived as most important in their

lives. In this way, they gain freedom from responsibilities now judged to be less compelling or more burdensome than before. The scope of their interests and concerns has shifted to fit their priorities (Corr et al., 2009:144).

- **Spiritual tasks**: Spiritual issues typically involve one or more of the following concerns. Meaningfulness people who are coping with dying may seek to identify, recognise, or formulate meaning for their lives, for death, suffering and for being human (Corr et al., 2009:146). Connectedness, illness and perhaps life threatening illness, threatens to break those connections that lend coherence to one's life. For example, one can feel disconnected to one's body. It is very important for a person in this situation to re-establish broken connections or to maintain and deepen existing connections. Transcendence refers to the ordinary things and especially to that which is of ultimate, surpassing worth. Like the issue of hope, the focus of hope may change over time (Corr et al., 2009:146).

1.25 CONCLUSION

This chapter focused on experiences of families regarding caring for family members who are terminal ill at their homes. With knowledge, skill, and compassion, health professionals can alleviate the reciprocal suffering of terminally patients and their families, by improving their quality of life until it ends. The practice of end-of-life care is noted to be broad and to be comprised of different practices that mainly include palliative care, hospice care and counselling. Although the WHO definition of palliative care is the most widely promoted, a key barrier to access palliative care is the misunderstanding among not only the public, but also among health care professionals.

The WHO (2010:15) emphasises that besides alleviating terminally ill patient's physical, psychological, and social distress through broad multidisciplinary approaches, end-of-life management for patients must be premised on excellent assessment, pain and symptom management, helping families in making important decisions about their family members, and offering supportive care during bereavement. The next chapter will focus on the research methodology and research findings.

2. CHAPTER 3: RESEARCH METHODOLOGY AND RESEARCH FINDINGS

2.1 INTRODUCTION

This chapter focuses on the research methodology that was applied during the research process and the findings emerged from the interviews on the experiences of families regarding caring for family members who are terminally ill at home at Ehlanzeni District in the Mpumalanga Province.

In chapter 1, the researcher outlined the proposed blueprint according to which the intended study was planned. In chapter 2, the researcher did a literature review in order to provide a theoretical base of knowledge concerning home care of terminally ill patients by their family members, different forms of palliative care and the role of the family as caregiver for the terminally ill patient.

The information that was obtained from the interviews with the participants was transcribed and analysed. The research findings are presented by means of themes and sub-themes that were identified during the data analysis and are supported by both verbatim quotes from the interviews and literature. The goal of the study is to explore the experiences of families regarding caring for family members who are terminally ill.

To attain the goal of the research study, the following objectives were pursued:

- To do a thorough literature study on family caregiving for a terminally ill patient, as well as the needs and challenges faced by family members while taking care of these patients at home.
- To explore the challenges family members are facing in taking care of terminally ill family members at home.
- To formulate recommendations based on the outcome of the study regarding support for family members that have to take care of terminally ill family members.

Nieuwenhuis (2007:51) states that qualitative research is mostly concerned with understanding the process and the social and cultural contexts which underlie various behavioural patterns, and is guided by one or more research questions. The research question therefore refers to what the researcher intends to find out or study. In the context of this study, the following research question was asked: **What are the experiences of families regarding caring for family members who are terminally ill living in Ehlanzeni District in the Mpumalanga Province?**

The following six specific areas are linked to the research question, and are also the main themes of the interview schedule:

- The family's understanding of the concept terminal illness.
- The impact of a terminal illness on a family system.
- The role of health professionals in assisting terminally ill patients and their families.
- Types of support services available within the community for terminally ill patients and their families.
- The challenges that family members and family caregivers experienced in taking care of a terminally ill family member.
- Cultural factors to be considered while caring for a terminally ill family member.

2.2 RESEARCH METHODOLOGY

2.2.1 Research approach

The researcher selected the qualitative research approach in order to explore and describe the experiences of families while caring for family members who are terminally ill at home, at the community of Ehlanzeni District in the Mpumalanga Province. Unlike the quantitative approach, this approach is ideal when dealing with people's real experiences, thoughts and feelings. The researcher aims to explore the experiences of family members who have to take care of other family members at home who are terminally ill. As indicated by Fouché and Delport (2005:75), this approach helped the researcher to understand the phenomenon and explore unknown terrain. The purpose of this approach is to construct detailed descriptions of social reality (Fouché & Delport, 2005:75) as experienced by the participants. Fouché and Delport (2002a:79) also explain that qualitative research aims to understand social life and the meaning people attach to everyday life. This study explored the meaning that family members attach to their experiences when they had to take care of terminally ill family members at home.

2.3 TYPE OF RESEARCH

Applied research was utilised in this research study. According to Fouché and De Vos (2005:105), applied research contributes to the scientific planning of reduced change in a troublesome situation, and aims to solve specific policy problems or help practitioners accomplish tasks; in other words, it is focused on solving problems in practise. Grinnell and Unrau (2008:25) further reiterate that the goal of applied research is to develop solutions to problems and the application of such solutions in practice. Fouché and De Vos (2005:105) state that most applied research findings have implications for knowledge development.

The research results from this study could assist the health professionals, home-based carers, and social workers in supporting family members who have to take care of terminally ill patients at home. Furthermore, becoming aware of the real experiences of family members who have to take care of other family members who are terminally ill can have positive implications for knowledge development.

2.4 RESEARCH DESIGN

The case study design was followed as it enabled the researcher to understand thoroughly the experiences of family members who have to take care of terminally ill family members at home.

According to Adams (2012:32), a research design aims to assist with at least four aspects of the study, namely:

- the questions that the researcher should study;
- the relevant data needed for the study;
- the type of data that should be collected; and
- how to go about analysing the data.

In a research study, a case being studied is referred to as a process, activity, event, programme, or individual or multiple individuals (Fouché, 2005:272). Where multiple cases are involved, it is referred to as a collective case study (Fouché, 2005:272), which is also the design the researcher used in this study. Furthermore, this research design supported the comparison of cases and concepts so that theories could be extended and validated (Fouché, 2005:272). Multiple cases were thus explored in this study to understand the real experiences of family members who have to take care of other family members at home who are terminally ill.

2.5 RESEARCH METHODS

2.5.1 Population

According to Strydom (2005c:193), a population is a set of entities that represent all measurements of interest to the practitioner or researcher.

The population in this study consisted of families who are taking care of family members at home who are terminally ill and who are residing in the Ehlanzeni District of Nelspruit, in the Mpumalanga Province. The terminally ill family members must all have been diagnosed with terminal illnesses and discharged from the Rob Ferreira Provincial Hospital and referred to the Nelspruit Hospice for palliative care due to other advanced clinical stages.

2.5.2 Sample and sampling methods

Sampling refers to the process used to select a small portion that will represent the total population (Strydom, 2011:223), which in this study were family members who have to take care of other family members at home who are terminally ill and who were willing to participate in the study. Punch (2005:55) defines a sample as a small size with no statistical grounds for guidance. The researcher utilised non-probability sampling (Grinnell, 2007:280), which entails that each unit in the sampling frame does not have an equal chance of being selected in the study. Thus, the researcher selected the participants with a specific purpose in mind. The following criteria were utilised for the selection of the participants:

- Male or female family members who were willing to participate in the study.
- Family members who were directly involved in taking care of family members at home that have been diagnosed by a medical doctor with a terminal illness.
- Participants between the age of 18 and 70 years.

- Participants whose family members had been discharged from the Rob Ferreira Provincial Hospital for at least three months.

The list of names of patients and their family members was provided by the Nelspruit Hospice, and the patients were contacted by the personnel of the Hospice to confirm their willingness to participate in the study.

2.5.3 Data Collection

The researcher used semi-structured interviews to gather the research data. Semi-structured interviews were organised around areas of particular interest, while still allowing flexibility in scope and depth (Greeff, 2005:292). The researcher decided to use a data collection method which allowed her to be spontaneous when asking questions. These questions were nearly always open-ended (Greeff, 2005:296) and allowed the participants to give detailed information of their experiences in taking care of family members who are terminally ill.

The themes in the interview schedule focused on the experiences of families caring for family members who were diagnosed with a terminal illness. The themes include the following: The family's understanding of the concept terminal illness, the impact of the terminal illness on the family system, the role of health professionals in assisting terminally ill patients and families, types of services available within the community for the terminally ill patient and their families, the challenges family members experience and cultural factors to be considered during a terminal illness.

The themes were further divided into sub-themes. The face to face interviews were conducted in the community of Ehlanzeni District where the participants resided. The arrangement was made and all participants were visited at their respective homes. All the participants were interviewed in their mother tongue. A total number of four participants were interviewed in Siswati and seven participants were interviewed in Xitsonga. The interviews were recorded with an electronic voice recorder with the consent of the participants.

2.5.4 Data analysis

Data analysis is defined by De Vos et al. (2011:339), as the process of bringing order, structure and meaning to the mass of collected data. The process was as follows (De Vos, 2011:334):

- **Planning for the recording data**

The researcher recorded the interviews using transcripts and a tape recorder. The researcher made use of an electronic tape recorder and ensured that all equipment was in good working order prior to data collection. Field notes were used to complement the tape recording. Notes were colour coded to keep track of dates, names and other important information. All this was conducted with the permission and with the knowledge of the participants.

- **Data collection and preliminary analysis**

As data was gathered, it was analysed (De Vos, 2011:335). The researcher planned to keep an open mind when collecting data because according to Patton (2002) in De Vos (2005:336), the recording and tracking of analytic insights that occur during data collection are part of fieldwork and the beginning of the qualitative process. While the researcher was collecting the data, she formulated ideas and interpretations of the content.

- **Managing or organising the data**

The researcher organised the information into computer files, and thereafter converted them into transcripts for analysis. The researcher converted the files to text units, e.g. sentences, and also developed the inventory to control the data gathered. All copies of the data were made and stored in a secure place.

- **Reading and writing of memos**

After data collection the researcher read the transcripts a number of times in order to understand the results before breaking them down into simpler entities. The emerging key concepts were written down. Furthermore, the researcher read the transcripts repeatedly and afterwards wrote memos and key notes in the margins of the field notes.

- **Generating categories, themes and patterns**

The researcher classified the information. Classifying means taking the qualitative information apart and looking for categories, themes or dimensions in the information (De Vos, 2005:338). The researcher reduced the data into small, manageable sets of themes in the final narrative as suggested in De Vos (2005:338).

- **Coding the data**: this step of the process required the researcher to abbreviate key words. During this step, data were also coded by means of certain colours.
- **Testing the emergent understanding**: in this phase the researcher evaluated the value of the data and its relevance to the research question. During this step, the researcher also evaluated the data according to the phenomenon being studied.
- **Searching alternative explanations**: this step requires the researcher to view the data from all possible angles. During this step the researcher searched for other explanations on the data and possible links between offered explanations.
- **Representation**: all findings were compiled into a research report. The researcher presented the final phase of data analysis in written form. The interpretation was done by means of a visual representation of the information, namely; tables, and it was presented in the form of verbatim quotes from the interviews to support the themes and sub-themes.

2.5.5 Trustworthiness

Trustworthiness in research is crucial in establishing the reliability and validity of a qualitative study. Qualitative research seeks to understand the subject being investigated to provide possible explanations for certain attitudes and experiences of different people. Trustworthiness is established by a variety of constructs or criteria of evaluation to ensure that the information gathered is both credible and valid for professional practice (Polit & Beck, 2008:537).

These constructs are credibility, transferability, conformability and dependability. According to Babbie and Mouton (2008:276), a qualitative study may be regarded as trustworthy when the experiences of the study participants are “accurately represented.” In an effort to ensure trustworthiness, the researcher used various strategies with the aim of placing the voice of participants as first priority to the research outcome (Lietz et al., 2006:420). The strategies that were followed were:

- Reflexivity: this refers to the ability to formulate an integrated understanding of one’s own cognitive world, especially understanding one’s influence or role in a set of human relations (De Vos, 2005:363). It was important for the researcher to reflect on her own experiences because it might have an impact on the research study (Lietz et al., 2006:448).
- Peer reviewing: this refers to the sharing of the process of data collection with a peer who acts as ‘devil’s advocate’ while questioning each stage of the research (Babbie & Mouton, 2008:277). The researcher engaged with social work colleagues outside the research project who did have some experience with the research population and subject matter. This was done in order to identify similarities and differences in their opinions on the research topic in an effort to identify any gaps in the data collected (Lietz, et al., 2006:450).
- Member checking: the researcher asked participants to check the transcripts to ensure that they agree with what had been recorded (Babbie & Mouton, 2008:277). This allowed participants to make sure that all data were recoded and correctly interpreted by the researcher (Lietz et al., 2006:453).

2.6 PILOT STUDY

The goal of a pilot study is to provide information which can contribute to the success of the research project as a whole. A pilot study is the specific pre-testing of research instruments, including the interview schedule. Therefore, a pilot study can be defined as both a feasibility study and the pre-testing of data gathering instruments (Strydom & Delport, 2011:394-395). Two participants were used to test the interview schedule and did not form part of the main study. Both participants were also selected according to the criteria for selection of the main participants. No changes were made to the interview schedule.

2.7 ETHICAL CONSIDERATIONS

According to Strydom (2005:57), ethics is a set of moral principles that is suggested by an individual or group, is subsequently widely accepted and offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students. Any activity which focuses on any aspect of human welfare has to give due consideration to ethical issues linked to basic human rights (Burns & Grove, 2009:185 and LaBiondo-Wood & Haber, 2010:254). The following ethical guidelines were adhered to during the research study:

2.7.1 Debriefing of participants

The easiest way to debrief participants is to discuss their feelings about the project immediately after the interviews (Salkind, 2000 in Strydom, 2005:67). This may help relieve any anxiety that participants may be experiencing as a result of being part of the study. All participants were debriefed after the interview. Only two participants were referred for counselling to the clinical social worker for further assistance after the interview.

2.7.2 No violation of privacy and confidentiality

Confidentiality ensures that the individual`s right to privacy is maintained (Polit & Beck, 2010:129 and LaBiondo-Wood & Haber, 2010:252). Privacy and confidentiality are extremely important ethical aspects that need to be maintained. Therefore participants must be able to trust the researcher enough to share information as honestly as possible. This will allow the research study to reach valid and meaningful conclusions that can be used in future research studies. All collected data in this study were handled in a careful way to maintain confidentiality and privacy. The researcher could not ensure full anonymity, as she met the participants in a personal interview. All the information that was shared during the interview was kept confidential and private. The results were presented in an anonymous manner to protect the identities of the participants.

2.7.3 Avoidance of harm

In terms of this study, participants were never at risk of physical harm. However some participants experienced some form of emotional distress due to the content of the interview. Only two participants were referred to the clinical social worker at Rob Ferreira Provincial Hospital for counselling.

2.7.4 Informed consent

Nobody should ever be coerced into participating in a research project. Thus participation must always be voluntary (Neuman, 2003 in Strydom, 2005a:59). According to De Vos et al. (2003:65), participants must be legally and psychologically competent to consent and free to withdraw from the investigation at any time. All participants signed consent forms before participating in the study. These consent forms clearly explain the purpose of the study, the aim of the study, the expected duration of the study, and the procedures to be followed as well as the possible advantages and disadvantages of the study. All participants were made aware of their freedom to choose whether to be part of the study or not. The participants were also informed about the fact that all content of the recorded interviews will be stored for 15 years at the University of Pretoria. All the participants signed consent letters.

2.7.5 Deception of subjects

Misrepresenting the purpose of the research is common, especially in cases of small qualitative projects (Strydom, 2005:60). In this study the researcher made the real purpose of the research study known to all the participants. It was important for the researcher to be transparent and honest with all participants about all aspects of the research. Strydom (2005:61) adds that if deception does occur, inadvertently, it must be rectified immediately after or during the debriefing interview. Thus, the researcher made sure that the participants received the correct information about the study. The researcher was honest with all the participants during the study by presenting the main purpose of the study to them. Furthermore, the researcher explained the benefits and the risks of them participating in the study.

2.7.6 Actions and competence of researchers

Ethically correct actions and attitudes for every research project should be considered under all circumstances and be part of the equipment of a competent researcher (Strydom, 2005:64). Firstly, the researcher was guided by a highly experienced research supervisor at the University of Pretoria. The researcher has also completed a degree in Social Work that required the completion of a research study. Thus, the researcher was experienced in research methodology and communication skills.

2.7.7 Release of publication of findings

The findings of this study were recorded in the form of a research report and submitted to the University of Pretoria. The release of the findings will occur in such a manner that no personal details of the participants will be recognised (Strydom, 2005:66). The completed research report will possibly serve as a guide for future researchers who wish to venture into the same or a similar research topic. Furthermore, the findings of the research will be shared with health professionals and other relevant stakeholders.

In addition to the ethical issues discussed in section 3.10, the researcher conducted the research according to the ethics and research guidelines of the University of Pretoria.

2.8 RESEARCH FINDINGS

This section will focus on the data that were collected during the research process. The data are presented in the form of participants' profiles and a thematic analysis of the themes generated from the research.

2.8.1 Biographic profile of the participants

Table 2.1: The biographic information of the participants

PARTICIPANT NUMBER AND PLACE AT EHLANZENI DISTRICT	GENDER AND RACE	AGE	RELATIONSHIP STATUS	RELATION TO THE TERMINALLY ILL PATIENT	PERIOD OF CARING
1 Ehlanzeni	Black Female	31	Single	Mother	2 years
2 Ehlanzeni	Black Female	49	Married	Uncle	4 years
3 Ehlanzeni	Black Female	49	Single	Uncle	3 years

PARTICIPANT NUMBER AND PLACE AT EHLANZENI DISTRICT	GENDER AND RACE	AGE	RELATIONSHIP STATUS	RELATION TO THE TERMINALLY ILL PATIENT	PERIOD OF CARING
4 Ehlanzeni	Black Female	45	Married	Mother	14 years
5 Ehlanzeni	Black Female	42	Married	Husband	5 years
6 Ehlanzeni	Black Female	49	Widow	Son	5 years
7 Ehlanzeni	Black Female	53	Single	Mother	2 years
8 Ehlanzeni	Black Female	59	Widow	Mother	8 years
9 Ehlanzeni	Black Female	62	Married	Husband	3 years
10 Ehlanzeni	Black Female	55	Married	Husband	6 years
11 Ehlanzeni	Black Female	39	Married	Child/ Daughter	5 years

All participants are female and reside in the rural community of Ehlanzeni District in the Mpumalanga Province, and are all people that were taking care of family members that were diagnosed with a terminally illness at the time the study was conducted. Six participants were married, and three out of the six participants who were married, were looking after their husbands as terminal ill patients. One participant was looking after her five-year-old child, one participant looking after her mother and another participant was looking after her uncle. The age of the participants ranged from 31 to 61 years of age and all were women. Two participants were widows whilst three of them are single persons. The period of time that these persons already took care of the terminally ill family members ranged from two (2) to 14 years. All participants were familiar and related to the terminally ill patients. The personal profiles of the participants are discussed below:

Table 2.2: Profile of research participants

Participant 1	Participant 1 is a 31-year-old woman who is not married. She and her mother live in a house in the district of Ehlanzeni along with her two siblings and her child. The participant completed grade 12 and had a certificate in computer literacy. Although she worked previously as a domestic worker, she had to stop working when she had to look after her mother who became terminally ill. She herself is a mother of a six-year-old girl who was born out of wedlock. Her mother was diagnosed with cancer (brain tumour) during 2015. The cancer was diagnosed after her mother collapsed at work. They are dependent on state health care services due to financial challenges. The local home base carers visit the family twice a month for psychosocial support.
Participant 2	Participant 2 is a 49 year old who looks after her 69-year-old uncle who was positively diagnosed with HIV/AIDS and Pulmonary TB in 2013. The participant completed grade 12, but could not further her studies due to financial strain. They live in the Ehlanzeni district of Mpumalanga. The Participant is married and has two adult children. She is a professionally trained caregiver, who is only working when her services are needed. Although the patient receives an old age grant, he has to make use of state health care services, as the family does not have any other source of income. The local home based care workers do visit the family on a regular basis.
Participant 3	Participant 3 is an unmarried woman who is 49 years old and a mother of three children who were born out of wed-lock. The terminally ill family member is an uncle who is 67 years old that was diagnosed with kidney failure. The participant attended school up to grade 11, and was not employed at the time the study was finalized. The family does not have a source of income, besides the old age grant received by the patient. The family also makes use of state health care while the local home based carers visit the uncle twice a month.
Participant 4	Participant 4 is a married woman of 45 years old. She lives with her husband, their two sons and her biological mother in the district of Ehlanzeni in Mpumalanga. This maternal grandmother is 72 years old and was diagnosed with TB of the spine in 1982 as well as with Dementia in 2008. She is responsible for the caring of her mother. The Participant was born in 1973 at one of the local Hospitals in the district of Ehlanzeni. She took care of her father who was suffering from cancer and who has since passed on in 2009, as well as her brother who was diagnosed with HIV and died in 2012. The participant is unemployed and is depending on her husband who owns a supermarket. The home base carers visit her mother

	twice a month. The participant and her mother often make use of private doctors because of the insufficient care they received from state hospitals in the past.
Participant 5	Participant 5 is a married woman, 45 years old, who looks after her husband of 51 years old. He was diagnosed with HIV/AIDS in 2012. The couple has three children. They live in the district of Ehlanzeni in the Mpumalanga Province. Before the participant started to look after her sick husband, she was employed at a local supermarket as a cleaner. Her husband who worked as a teacher was granted ill health retirement in 2012 due to medical reasons after he could not walk anymore. The participant is affiliated to the Zion Christian church (ZCC), whilst her husband believes in traditional religion. Although they had a medical aid, it became exhausted due to the fact that he was admitted to Medi-clinic for a long period. They are depending on the state health care services. They are receiving support from the local home based care workers on a weekly basis.
Participant 6	Participant 6 is a 49-year-old woman who looks after her 25-year-old son who was diagnosed with Schizophrenia and TB. The participant and her son live in the district of Ehlanzeni in the Mpumalanga Province. This participant never went to school. The son tested HIV positive in 2014 and receives a disability grant. The participant has two other children, and also has to take care of two grandchildren. The participant is affiliated to the Zion Christian Church (ZCC), and her son does not participate in the activities of the church. They are making use of the service of the state hospital and home base carers often visit them.
Participant 7	Participant 7 is a 53-year-old woman who was never been married. She has no children of her own. She was working at a farm in Limpopo, but had to resign in 2015 when her mother became terminally ill. Her mother is 93 years old and was diagnosed with Diabetes. She is not able to look after herself anymore. Due to the latter, the participant is not working anymore and is dependent on her mother`s old age grant. The participant is not affiliated to any church. The participant and her mother are making use of state health care services and community home based carers visit them once a month.
Participant 8	Participant 8 is a 59-year-old widow who lives in the district of Ehlanzeni in the Mpumalanga Province. She looks after her mother of 81 years who was diagnosed with Diabetes and Alzheimer’s in 2012. She is also a mother to three children. The participant is a member of the Nazarene church but her mother is not affiliated. The participant is unemployed and is dependent on her adult children who assist her financially. The participant and her mother make use of the state health care services and receive once a month

	support from home based care.
Participant 9	Participant 9 is a 62-year-old woman who looks after her 76-year-old husband who was diagnosed with Diabetes and epilepsy in 2016 who also had a stroke. They live in the district of Ehlanzeni in the Mpumalanga Province. They have been married for 42 years and have six children They are staying next to relatives who assist her in taking care of her husband. The participant never attended school and is unable to read or write. Both are receiving an old age grant and indicated that the amount is not enough to cater for both their needs. Some of their children often assist them financially. They are affiliated to the Zion Christian Church (ZCC). They receives support from home-base carers once a month and they do make use of state health care services.
Participant 10	Participant 10 is a 55-year-old woman who lives in the district of Ehlanzeni in Mpumalanga, who has to look after her 67-year-old husband who was diagnosed with HIV/AIDS and Diabetes during 2015. They have been married for 32 years and have two children and two grandchildren. The participant also tested HIV positive in 2013. The participant passed grade 6 and is not employed. She does some gardening and sells her vegetables to community members. The participant attends church services every Sunday. Home based carers visit the family twice a month and both the participant and her husband make use of state health care services.
Participant 11	Participant 11 is a married female of 39 years who looks after her three-year-old child who was diagnosed with Pneumonia and Pulmonary TB due to HIV/AIDS. The child is also a disabled person and cannot walk or sit properly. She has two other children who also live with her. The participant attended school and passed grade 11. Her husband is self-employed as a Bricklayer. The participant receives a child support grant for her two children. She was working at a Shoprite super market, but had to resign when her child became seriously ill. She is a fulltime member of Zion Christian Church (ZCC). The participant and her child make use of state health care services and do receive support from local home-based carers. They also attend a support group at the hospital at the HIV/AIDS clinic as well as the rehabilitation unit twice a month.

2.9 FAMILIES AS CARE SYSTEMS TO TERMINALLY ILL PATIENTS

This section focuses on the families who are caring for family members with terminal illnesses, the specific type of terminal illness, the period of caring and caregiving, age, gender, the relationship between the patient and family member, and the level of education of the family member.

- **Specific types of terminal illness**

The terminally ill patients in this study were diagnosed with different types of chronic illnesses. A total number of five patients were diagnosed with HIV/AIDS and TB, one patient had a stroke and was also diagnosed with epilepsy, one with TB of the Spine and Dementia, one with Diabetes, one with Schizophrenia, one with Diabetes and Alzheimer, one with cancer and a brain tumour and one with kidney failure.

The 2013 Global Burden of Disease Study estimated that almost 30% of all deaths worldwide were caused by CVD. However, recent evidence from Europe studies suggests that in some countries cancer has overtaken CVD as the leading cause of death. CRF also referred to as chronic renal disease (CRD), is a growing health care concern and a major public health burden in developed and developing countries. It is affecting more than 19 million people (adults and children) in the USA, and the prevalence of CRF is expected to double within 10 years, especially among elderly people (Davison, 2007:17 and Nahas & Levin, 2009:77). Cameron (1996:29) added that many people who are dying of kidney failure are over the age of 70 years and a notable feature of kidney failure is that, the incidence rises steeply all the way from 15 to 90 years of age.

A stroke, also known as a cerebrovascular accident (CVA), occurs when blood flow to the brain is interrupted. This could either happen when a blood vessel in the brain ruptures, causing bleeding, or becomes blocked by a blood clot. The affected brain cells then start to die because of a lack of oxygen and other nutrients. The severity of the stroke varies from a passing weakness or tingling in a limb, to profound paralysis, coma or death. Premature deaths caused by heart and blood vessel diseases in people of working age (35-64 years) are expected to increase by 41% between 2000 and 2030. The negative economic impact of this will be enormous.

Strokes are the third leading cause of death and the main cause of disability of adults in developed countries (Polivka, Rohan, Sevcik & Polivka, 2014:1). This is due to the fact that many people do not know that they are at risk of having a stroke until it actually happens to them. According to Clark (2008:504), dementia refers to a loss of intellectual function in multiple domains including memory, problem solving ability, judgment and others. It is a general term used to encompass cognitive deficits that include progressive memory loss and at least one other symptom such as aphasia (difficulty with written or verbal communication), apraxia (inability to correctly use objects) or agnosia (loss of comprehension of auditory, visual or tactile sensations). Tuberculosis, commonly known as TB, is a contagious and an often severe airborne disease caused by a bacterial infection (WHO, 2012:103). TB typically affects the lungs, but it may also affect other organs in the body. It is usually treated with a regimen of drugs taken for six months to two years, depending on the type of infection.

- **Period of caring**

The period of providing care to the family members with a terminal illness ranges from two years to fourteen years. A total number of two patients were cared for a period of two years, two patients for three years, one patient for four years, three patients for five years, one for fourteen years, one for six years and another for a period of eight years.

According to World Health Statistics (2015:120), it is estimated that of the 58 million people who die every year globally, 35 million will experience a prolonged, advance illness. Unfortunately, South Africa is not exempt from this reality. Taking into account the impact of the HIV/AIDS pandemic and predictions by the Cancer Association of South Africa, the number of annual cancer diagnoses in South Africa could soar from approximately 100 000 to half a million within half a century (WHO, 2012:34).

- **Age**

The age of the participants ranged from the age of 31 years to 62 years with the average age of 39 years. Only two participants were between the ages of 30 to 39. Five of the participants were between the age of 40 to 49 years of age and four were between the age of 50 to 65 years of age.

- **Gender**

All participants who are caring for family members with terminal illnesses are females. Seven participants are caring for male terminally ill patients, two participants were taking care of their children and three participants are looking after their mothers.

- **Relationship between the patient and the family member**

All participants are related by blood to the terminally ill patients. Richter (2007:4) defines families as societal groups that are related by blood (kinship), marriage, adoption, or affiliation with close emotional attachments to each other that endure over time and go beyond a particular physical residence. Furthermore, a family is a group of two or more people (one of whom is the householder) related by birth, marriage, or adoption who live together (Belsey, 2005:11).

- **Level of education**

A total number of three participants have completed matric, two completed grade 11, one grade 10, one grade 4, one grade 6 and another three participants have never gone to school and are unable to read or write. The table below discusses their educational level and the highest level passed:

Table 2.3: Educational level obtained by the participants

PARTICIPANTS	EDUCATIONAL LEVEL OBTAINED BY THE PARTICIPANTS
1	Grade 12
2	Grade 10
3	Grade 11
4	None
5	Grade 12
6	Grade 12
7	None
8	Grade 4
9	None
10	Grade 6
11	Grade 11

2.10 THEMES AND SUB-THEMES

Research findings are discussed according to themes and sub-themes that were identified. The table below provides an overview of the themes and sub-themes that were generated from the research.

Table 2.4: Themes and sub-themes of research

THEMES	SUB-THEMES
Theme 1 The family's understanding of the concept terminal illnesses	• Causes of terminal illnesses • Symptoms • Medical treatment and prognosis
Theme 2 The effect of a terminal illness on a family system	• Physical affects • Psychological affects • Social affects • Financial affects • Positive affect of a terminally illness on the family system
Theme 3 Role of health professionals in assisting terminally ill family members and their families	• Social work services • Medical Doctor services • Spiritual carers services • Psychologist services
Theme 4 Types of services available within the community for the terminally ill patients and their families	• Hospice rendering services • Support groups services • Community home-based care services
Theme 5 The challenges family members experienced	• Challenges for children • Challenges for family caregivers • Fears experienced by family members
Theme 6 Cultural factors to be considered while caring for a terminal illness	• Death as taboo subject • The use of traditional healing

2.11 DISCUSSION OF EMPIRICAL DATA

The data that were collected during the different semi-structured interviews will now be discussed according to the different themes and sub-themes:

2.11.1 Theme 1: The family’s understanding of the concept terminal illness

This section focuses on the family member’s understanding of the concept terminal illness as well as the nature, causes and prognoses of the different terminal illnesses that were diagnosed. A terminal illness can be defined as a status assigned to a person who has been diagnosed with an illness and is expected to die within a certain time frame, usually six months (WHO, 2012:21). A terminal illness can also be referred to as an illness or injury that will inevitably result in the death of a patient. The participants reported that they understood the condition of their terminally ill family members as they are looking after them. Some of the participants explained it as follows:

> **Participant 4**
> *“I know it is not nice, but I have to remain strong. During the past I was looking after my relatives with similar illnesses and they didn’t make it. They died after a short period of time. Now I understand that it is rare for a person to survive with a terminal illness.”*
>
> **Participant 3**
> *“The doctor told us as the family that there`s a high possibility that my uncle cannot make it, and that he can die at any expected time.”*
>
> **Participant 2**
> *“I have a lot of experience as a trained caregiver and I have been looking after people with terminal illnesses. Once they reached this stage, they normally die. My role is to provide the quality of care until the last day, and ensure that he die in peace.”*

The findings correlate with the sentiments of Pass and Morrison (2006:117), namely that a terminal illness is a disease that cannot be cured or adequately treated, and that is reasonably expected to result in the death of the patient within a short period of time. This term is more commonly used for progressive diseases such as cancer or advanced heart diseases, HIV/AIDS and CRF. In popular use, it indicates a disease that eventually ends the life of the sufferer (Pass & Morrison, 2006:117). Patients who have such an illness may be referred to as terminal patients, terminally ill or simply terminal. Often a patient is considered terminally ill when their estimated life expectancy is six months or less, under the assumption that the disease will run its normal course.

The research findings revealed that all the terminally ill patients were bedridden and they needed full-time care. Seven of the patients involved reported that they were informed by a health professional that they are not going to make it due to their health condition. Four explained that a health professional explained to them that there is nothing that can be done to improve their condition, and that it is the main reason for them being discharged from the hospital. All of the participants reported that they could observe the condition of their terminally ill patients and knew that things are not in good terms before they were informed by a health professional.

2.11.1.1 Sub-theme 1.1: Causes of terminal illnesses

A total number of five participants did not understand the nature or the main causes of the specific terminal illness. Four of the participants did indicate that the information of the sickness was explained to them by a health practitioner, but that they did not understand the explanation initially. Some of the participants explained their discomfort in this regard as follows:

> **Participant 1**
> *"I thought maybe she was suffering from a stress related illness as she had several challenges during the past, and I believed that it was just for temporary bases. I was hoping that she will get better as time continued hence we were giving the wrong medication because of a lack of information."*
>
> **Participant 5**
> *"It was very difficult for me to understand his condition as he was presenting with many symptoms that I never experienced in life."*
>
> **Participant 6**
> *"I don't understand the kind of this illness. When it started the person was very aggressive and uncontrollable. He was behaving like an animal (using both hands and legs). I then requested people to take him to the hospital and that's where the doctors diagnosed him with Schizophrenia. Later he complained with chest pains and was diagnosed with TB and HIV/AIDS."*
>
> **Participant 8**
> *"I believe that my mother has been witched. In most cases she talks alone and she will take a walk without knowing where she is going. Sometimes our neighbours will call us to come and fetch her during the night. Some of my family turn to associate her medical condition with a cultural illness."*

Participant 3

"No I don't have any clue on what is happening, although the doctors and nurses at the hospital explained to me what causes this condition to be like these."

Participant 9

"I don't know, I'm still need to know because no one did explained to me what causes the condition to be like these. Initially we took him to the traditional healers because of the lack of understanding"

The findings show that participants were not familiar with the nature of the illnesses and the study results show similarities with the findings of other studies cited in literature. McDaniel et al. (2014:257), state that this phase is associated with initial indicators of an illness or a disease and the tendency exists that, people often ignore these indicators hoping that things will get better. Patients may try to minimise effective responses to the presence of the disease and, decide to investigate the significance thereof. Furthermore, they will seek out medical or professional sources for advice to investigate or diagnose the potential problem.

2.11.1.2 Sub-theme 1.2: Symptoms presented

A total number of five participants understood the possible symptoms of the patients suffering from different illnesses. Six of the participants did not have any knowledge of the specific symptoms. Some participants reported on general symptoms which are more related to the end-of-life stage and are not specific symptoms related to a specific illness. The participants reported as follows:

Participant 10

"I have to force my husband to eat food, and he became aggressive because he doesn't need it. Sometimes he cannot even swallow it, and if I keep on feeding he just vomit."

Participant 4

"It seems she has memory loss. In most cases she tells us things that does not make sense in a normal life. Some of my relative are no longer willing to visit us as my mother accused them of the things they have never done."

Participant 5

"I left my job as I have to look after him full time. He loss control in terms going to toilet, everything it's done while asleep."

According to Khosla et al. (2012:241), the above-mentioned common symptoms are presenting during the end-of-life stage and are not specific symptoms related to a specific terminal illness.

The National Cancer Institute (2015:138) explains that good management of symptoms in the terminal phase is also important and is one of the main concerns of patients and their families. The physical comfort of dying patients requires thorough assessment, excellent nursing care and careful prescribing. The following are the common symptoms in end-of-life care which the participants also confirmed:

Table 2.5: Common symptoms in end-of-life care

Common Symptoms in End-of-Life Care	
Symptom	**How to provide comfort**
Drowsiness	Plan visits and activities for times when the patient is most alert.
Becoming unresponsive	Many patients are still able to hear after they are no longer able to speak, so talk as if he or she can hear you.
Confusion about time, place, or identity of loved ones	Speak calmly to help re-orient the patient. Gently remind the patient of the time, date, and people who are with them.
Loss of appetite, decreased need for food and fluids	Let the patient choose if and when to eat or drink. Ice chips, water, or juice may be refreshing if the patient can swallow. Keep the patient's mouth and lips moist with products such as glycerine swabs and lip balm.
Loss of bladder or bowel control	Keep the patient as clean, dry, and comfortable as possible. Place disposable pads on the bed beneath the patient and remove them when they become soiled.
Skin becoming cool to the touch	Warm the patient with blankets but avoid electric blankets, or heating pads, as they can cause burns.
Laboured, irregular, shallow, or noisy breathing	Breathing may be easier if the patient's body is turned to the side and pillows are placed beneath the head and behind the back. A cool mist humidifier may also help.

(Source: The National Cancer Institute, 2015:138)

According to Kholsa et al. (2012: 241), the above mention symptoms are presenting during the end-of-life stage.

Nearly all participants reported that terminally ill patients, who are bedridden, often act out of control. They also reported that they do not want anything which including food, especially when they are in pain. Pain is the dominant symptom in the advanced stages of diseases (Kholsa, Patel & Sharma, 2012:239). It can cause a patient to become anxious, uncomfortable and impatient.

2.11.1.3 Sub-theme 1.3: Medication and prognosis

Four participants understood ARV treatment very well, as they were also diagnosed with HIV/AIDS and were also receiving treatment for it. One participant reported that she couldn't understand the treatment, as her mother was suffering from Dementia and TB of the spine until the doctor explained it to her. The participants explain their experiences as follows:

> **Participant 2**
> *"When I wake up early in the morning before I give him treatment, I prepare soft porridge and feed him, then after that I give the treatment.''*
>
> **Participant 3**
> *"It becomes a huge challenge to me in case when he is vomiting and with diarrhoea, because he then becomes week and it becomes so problematic to give treatment in that regard.''*
>
> **Participant 4**
> *"No I don't think there's medication for Dementia. We have been to different doctors while my father was still alive but the situation remained the same."*
>
> **Participant 6**
> *"Maybe it's late already; if we knew he was supposed to be taken to the hospital as soon as possible."*
>
> **Participant 9**
> *"Sometimes when his condition becomes worse and so impossible for him to take medication, I just take him to the hospital for further assistance."*
>
> **Participant 5**
> *"At this stage we are just giving the medication, but I can see that there's no improvement in fact the condition becomes worse. I then assume that may be the doctor is afraid to tell us that there`s nothing that can be done at this stage, but as the family we can see that we are going to lose him."*
>
> **Participant 1**
> *"I don't think there's any medication that can help her, or if maybe she can be admitted full time in the hospital."*

> **Participant 10**
> *"I think the nurses and doctors are going to assist, he normally improve when he adhere to his medication. It becomes worse after he defaulted the treatment."*

Five participants reported that they received information from the health professionals on how to give treatment to their loved ones. Eight participants reported that some of the treatment are supposed to be taken during the night at eight o'clock. All participants reported that they were informed that they must not give the patients medication on an empty stomach, as they have to feed them first. Two participants reported that they have implemented everything as specified by the health professionals but there is no improvement. Three participants reported that the process of improvement is very slow.

2.11.2 Theme 2: The effect of a terminal illness on a family system

The condition of terminally ill patients in general affects the family as a whole both patient and family members. Research indicates that in many families the caregiver is a patient's wife, husband, mother, daughter, sister or extended family member (Gallagher-Allred, 2009:57).

NORD (2015:52) indicated that a caregiver's competence or perceived competence in caring for a loved one can affect the caregiver's quality of life. A caregiver's perceived competence can be affected by many related variables, like family income, their loved one's quality of life, and the balancing demands of other family members. There is no doubt that taking care of a terminally ill family member, has a physical, psychological and financial impact on the family system. The physical demands on families are closely related to medical variables such as the stage of the disease, the level of symptomatology, the functional ability of the patient, and the side effect profile. The psychological impact of terminal illnesses like cancer can be ameliorated by social support, financial security, and stability at work. Given the increasingly chronic nature of cancer, families may find that taking care of the terminally ill patient is time consuming and can lead to feelings of social isolation (Rocker, Puntillo, Azoulay & Nelson, 2010:152-153).

2.11.2.1 Sub-theme 2.1: Physical effects

In exploring the physical effects of the terminally ill family member on the family system, participants were asked to narrate their perception of their own experiences and challenges. Nine participants stated that their experiences have a negative effect on their general health status. They further explained that they do not have time to rest, and they experienced some form of fatigue, headaches, stress related illnesses, general body pains and hypertension. Participants shared the following views concerning experiences in this regard:

> **Participant 9**
> *"I also have a medical condition of diabetes and high blood pressure. During the night I can't rest. I have to wake-up in the middle of the night and assist him by changing his nappy and turn him to sleep on the other side."*
> **Participant 4**
> *"I always feel tired, with general body pains and I also have kids and husband that needs me."*
> **Participant 5**
> *"I'm HIV positive and on ARV's and I don't have enough time to rest, I have to bath him, feed him, clean and cook everyday."*
> **Participant 1**
> *"My challenge is during the hospital visit, I have to pick her up and I don't have enough power as I'm always exhausted."*
> **Participant 9**
> *"Since caring for him, I have lost weight and I'm always worried about his condition and my condition as well."*

The physical demands of caring for a patient with a terminal illness are often substantial and burdensome (Kristjanson, 2009:141). The American society of Clinical Oncology (2013:09) states that caregiver burden is defined as the extent to which caregivers feel that their emotional or physical health, social life, and financial status have suffered as a result of caring (Kristjanson, 2009:141). This implies that caregiving has a significant impact on caregivers' well-being and their needs are frequently considered secondary to those of the patient or are overlooked. Some research has suggested that caregivers of people with cancer may have more unmet care needs than patients (American Society of Clinical Oncology, 2013:09). Many caregivers report that the provision of personal hygiene and the administration of medication are particularly difficult to handle (Kalula &

Petros, 2011:31). A recent review by Stenberg et al. (2014:91), found that the most prevalent physical problems reported by caregivers are sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss. In an Australian study of caregivers, more than half reported that caregiving had directly affected their overall physical health, including tiredness and exhaustion (Stenberg et al., 2014:91). These are also the symptoms that the participants in this study reported.

2.11.2.2 Sub-theme 2.2: Psychological effects

The family members who care for terminally ill patients experience psychological discomfort such as loss of concentration, frustration, stress related illnesses and guilt. Corr et al. (2009:143), state that when family members are faced with these, many helpers would experience discomfort and would be unsure of the way they have to execute their caring. More research indicate in their studies that caregivers report emotional distress, deriving from feelings of loneliness, fear, guilt, helplessness and a lack of control in their everyday life (Vanderwerker, Laff, Kadan-Lottick, McColl & Prigerson, 2005:68).

This study confirmed how caring for a terminally ill person may affect family members. The results generated were consistent among the participants. None of the participants feels comfortable with the medical condition and they associate caring for family members with a terminal illness as a burden. They also explained that they have to take the responsibility for it due to the fact that they do not have a choice. Nine participants reported that they experience stress, fear and loneliness whereas three participants stated clearly that caring for a terminally ill patient is so stressful that they would like to put the patient in a caring facility. The following phrases indicate the experiences of the participants:

> **Participant 4**
> *"I don't have peace of mind when I look at my mother's condition and I`m the only one who are left in the family as all other family members passed away. What's going to happen to her in case I die or if any unforeseen can happen to me."*
>
> **Participant 5**
> *"It causes a lot of stress in my life, what if he die, it means my kids will not have a father for the rest of their life."*

> **Participant 9**
>
> *"I always put a blame to myself that maybe I'm not doing enough so that he can recover, I also feel guilty for not affording all his needs."*
>
> **Participant 11**
>
> *"I get frustrated because my daughter cannot walk and she is 5 years old and she is HIV positive. I always blame myself that I was not supposed to be pregnant as I knew I'm HIV positive. I sometimes feel helpless as I have to take her for regular check-ups to the occupational therapist and physiotherapist for training, and to the doctor on my own. It makes me feel sad, lonely and angry for everything that is taking place in my life. The absence of relatives and in-laws makes me to feel isolated."*

The research results are similar to the findings of other studies in the literature. The reality is that the family caregiver may experience feelings of depression, helplessness and hopelessness, apathy, dejection, and discouragement (Livneh & Wilson, 2011:201). Signs of depression include sleep disturbances, change in appetite, difficulty in concentration, and withdrawal from society. According to Livneh and Wilson (2011:202), guilt can be described as self-criticism or blame. Patients or family members may experience guilt if they believe they contributed to or in some way caused their illness. A good example may be that of a patient who developed lung cancer or emphysema after years of using tobacco or those who experienced spinal cord injuries owing to an accident that occurred because they were driving while intoxicated (Kovac et al., 2012:50).

Family members and terminally ill patients may experience anger at themselves or others for perceived injustices or losses associated with their conditions (Kovac et al., 2012:48). They may believe that the terminal illness was caused by negligence or that their condition was avoidable. If they perceive themselves as victims, their anger may be directed towards the persons or circumstances they blame for the condition, but if they believe that their own actions were partly to blame for the terminal illness, the anger may be directed inwards (Livneh & Wilson, 2011:201). Anger can also be the result of frustration and patients may vent their frustration and anger by displacing hostility towards others even when those parties have no relationship to the development of the terminal illness and no influence over its outcome. Anger may also be the realisation of the seriousness of the situation and associated feelings of helplessness. At times anger may not be openly expressed but rather hidden in quarrelling, arguing, complaining, or being excessively demanding, in an attempt to gain control (Livneh & Wilson, 2011:201). Helping patients to express anger in appropriate ways and enabling them to regain a sense of control over their situation can help to resolve anger.

The presence of a terminal illness within the family can pose a threat because of the potential loss of function, loss of love, loss of independence and loss of financial security. Threat causes anxiety and some family members fear the unknown or unpredictability of the condition, which on the other hand provokes anxiety (Livneh & Wilson, 2011:199). When conditions are life- threatening, fear and anxiety may be associated not only with loss of function, but also with loss of life. Fear and anxiety associated with a terminal illness can place a patient in a state of panic, rendering them psychologically immobile and unable to act (Livneh & Wilson, 2011:199). It is important to note that the fear experience by family members may have both rational and irrational aspects. Fear and anxiety are often future oriented, having to do with perceptions of what could occur rather than based on what is actually known in the present (Livneh & Wilson, 2011:199).

It is very clear from the results of this study that family caregiving to the member of the family with a terminal illness at home remain a challenge. It can be detrimental to the psychological and emotional wellbeing of the family caregivers.

2.11.2.3 Sub-theme 2.3: Social affects

Looking after family members with a terminal illness can have a negative affect on the social functioning of family members. Social isolation of relatives and in-laws, restriction on social activities and the lack of social and emotional support remain as the most important negative outcomes for the majority of family caregivers.

The study explored several issues on social functioning. Nine (9) out of 11 of the participants reported that they do not have enough time for themselves due to the fact that they are looking after the terminally ill patient within the family. They also indicated that it demands almost all of their time, as they have to complete all the work in general. Nine (9) participants indicated that they do not have enough time for their families and relatives, whilst six (6) out of the 11 participants stated that they felt like they neglected their friends and even their own kids, as they could not spend enough time with them. Three (3) participants are not married but they do have fiancés or boyfriends. They reported that they were experiencing challenges too. Two (2) of the six (6) participants who are married, experienced a negative impact on their marital relationships. Participants often experienced feelings of isolation and a lack of social support from relatives, family-friends and community members. Eight (8) participants reported that they were receiving spiritual support from their churches which they are affiliated with, and that it plays an important role in their lives. The participants explained their experiences in this regard as follows:

> **Participant 4**
> *"I don't have time for my husband and kids. During the past we use to go out for holidays at Kruger Park but now things have changed. Though my husband is supportive, but I can feel that our relationship is no longer the same."*
>
> **Participant 11**
> *"I don't have time for my friends. I use to meet with other women once a month as the team of the community burial society. I'm no longer part of them due to a lack of enough time. They also complain that it seems as if I have neglected them."*
>
> **Participant 10**
> *"I feel isolated, emotionally I'm not fine, I used to attend women church services every Wednesday, funerals and other important traditional functions. Now I'm no longer attending as my husband needs me and I have to feed and bath him on a regularly basis."*
>
> **Participant 5**
> *"I don't receive any social support from my relatives, in-laws and community members. I just feel alone and that no one cares about our lives. Only the church members who visits us."*
>
> **Participant 8**
> *"It's hard for me to cope, even if I experience difficulties. I have no one to share with. Sometimes even if I share with others they are not assisting me with anything."*
>
> **Participant 1**
> *"I have a boyfriend, the father of my child and as we are not staying together we use to visit each other. Since I'm looking after my mother I don't have time to see him. I'm not coping well with the situation and its affects me a lot."*

The research findings revealed information similar to that which is found in the literature. Social isolation is one of the most widely self-reported problems associated with family care giving (Vanderwerker et al., 2005:69). These impacts resulted in loneliness, changes in family and other relationships, a sense of grief and loss, and limited time for personal relationships. Stenberg et al. (2014:118), stated that even couples may struggle to manage the stress and challenges of cancer, as well as changes in their relationships brought on by the cancer diagnosis and such stress might lead to tension and conflict within the relationship. The American Society of Clinical Oncology (2013:09) suggests that early intervention and support may prevent the abuse of caregivers from occurring or reoccurring. Finally, while extended family members may be a major source of support for caregivers, it cannot be assumed that these interactions will always be positive. The blend of traditional roles with care responsibilities can result in changes to family dynamics, presenting new challenges for families and at times generating conflict.

2.11.2.4 Sub-theme 2.4: Financial affects

None of the participants indicated that they are employed on a full-time basis. Five (5) out of 11 participants were temporarily employed, but they left their jobs in order to look after their relatives. Three (3) participants were working at a supermarket, one (1) was working at a farm in Limpopo, and one was working as a domestic worker. One participant indicated that she has a certificate in caregiving but she does not have a permanent post and that she is only called to work if there is a need for. Two (2) participants were recipients of a social grant, whilst two (2) others were never employed and one (1) participant was self-employed by selling vegetables from her garden. The findings indicated that family caregiving of the family members with terminal illnesses at home had a negative effect on their financial status. The participants explained their experiences as follows:

> **Participant 1**
> *"I am suffering financially. I was depending on my mom as she was working before she fell ill, I was also a domestic worker. Now we don't have any financial income but depending on a child support grant for kids. It makes our lives to be difficult as we fail to meet some family basic needs such as food and electricity."*

Participant 5

"I feel helpless, as my husband was a professional teacher with a better salary, now I can't afford to pay the school transport for my kids. My husband use to buy toys and presents for my kids. Now it causes a lot of frustrations to my kids as well."

Participant 9

"I'm always so financially stranded and I have to hire transport for his hospital visit twice a month and his condition complicate during the night. They charge the total amount of R150 to R250 per trip. I become stranded as sometimes I don't know where to get the money. My relatives and in-laws are not supportive financially."

Participant 10

"It worries me a lot, because health professional told me to give him fruits and more of vegetables, but all needs money. Sometimes I think a lack of proper diet may affect his recovery."

Participant 4

"Most of the time, the doctor prescribes medication that is always out of stock within the government hospital. I have to buy from my pocket. In most cases the amount is R250 to R600 per packet of pills. It cost me a lot."

Participant 3

"I use to receive pampers from local home based care. Sometimes they don't have them and we cannot manage her without pampers. If they didn't gave us, I have to buy it."

Participant 1

"Sometimes the church contributes money and they give it to me during the visit, but it is not enough to cover the family needs."

Caregiving of family members creates a financial burden for family members, both in outright expenses and in loss of income and benefits (American Society of Clinical Oncology, 2013:11). Additional costs associated with care may include the purchase of equipment, bedding, home alterations, medical bills, rental equipment, respite, hygiene supplies and pharmaceuticals (Kristjanson, 2009:148). Caregiving also appears to reduce a person's chance of being employed, and many caregivers are unable to work, need to take leave without pay, have fewer work hours, are in lower paying jobs, or work from home to manage the caregiver demands (American Society of Clinical Oncology, 2013:11).

2.11.2.5 Sub-theme 2.5: Positive affect of family care giving on a family system

The majority of the participants reported that a family needs to provide love and care for each other. Participant two (2) stated that families must not only love their loved ones when life is good, but they have to show and provide care even in the most difficult times. Participant seven (7) explained that she will never leave her mother but would, rather suffer together. The study confirmed that many participants found some meaning in providing care for the family member with a terminal illness. They explained it as a symbol of love and the feeling of togetherness as a family.

Ownsworth, Henderson and Chambers (2010:116) indicate that although caregivers often report experiences of shock, disbelief, anger, distress, fear, and depression in response to caring for terminally ill family members, they felt that caring for family members can also be an experience that can produce positive emotions. During some interviews with participants on this theme the following responses were shared:

> **Participant 7**
> *"I won't get tired in taking care of my mother. It will be difficult to choose between my mother and my husband as they are all very special to me. I always make sure that I'm available for them and I feel great to be with them. Before my father passed on, he was the one responsible in taking care of her and presently I'm the only one left in the family. I feel proud in caring for her."*
>
> **Participant 5**
> *"I think looking after him keeps the family going. Our kids have trust in me that I will make it. I can't appoint someone to look after him while I'm available. To me it is a symbol of love, and this is what I promise to him during our marriage that I will never leave him."*
>
> **Participant 4**
> *"I love my mother a lot, I left my job so that I can be full-time on her. Whenever she's happy, I also feels happy. We agreed as a family that we can't leave her to other's we are going to take care for her till the will of God happens."*
>
> **Participant 2**
> *"I enjoy looking after my uncle. There was no one willing to look after him, but I made a decision that I will look after him and I don't need a reward from any one. I'm doing this for myself and the family. I love him irrespective of being sick or not."*

> **Participant 11**
>
> *"I love my child, and I believe God will made miracles one day. I don't know how but I still have that hope that thinks will not remain the same. I gave birth to my child because I wanted to be with her. I am doing this for me and the family."*

Despite the burden of family caregiving, the majority of the participants described family caregiving as a symbol of love and care. Ownsworth et al. (2010:121), state that according to an Australian study, 60% of caregivers were able to identify the positive aspects of their roles as caregivers. When patients' symptoms were minor, the time together was described very emotively as "precious time," which allowed the exploration of emotions and an expression of love for the patient. Post bereavement caregivers in another Australian study reported the caregivers being proud, pleased, and satisfied that they had managed the caregiving role. Lambert, Harrison and Smith (2012:224) indicate that happiness over quality time spent with the patient, the ability to explore and resolve issues, and feelings of value and self-worth have all been reported by caregivers. In addition, it has been suggested that caring for the patient may help caregivers to accept the death of the patient and work through their grief (Lambert et al., 2012:230).

In conclusion, the study demonstrated that the experiences of families regarding caring for family members with a terminal illness provide them the opportunity to love, respect and understand the value of each other within the family system.

2.11.3 Theme 3: The role of health professionals in assisting terminally ill family members and their families

The majority of the participants explained that community care is the most common solution to support their family members who are terminally ill. Seven (7) out of the 11 participants explained their experiences with state health care as positive. Four (4) participants described the public health care services as insufficient. The theme is divided into five sub-themes.

2.11.3.1 Sub-theme 3.1: Social work services

Singer and Bowman (2009:63) indicated that counselling in end-of-life care offers counsellors the opportunity to identify the stressors in people's lives as well as coping strategies for patients and their families.

The majority of the participants were not familiar with social work services. They explained that they were never referred to social workers by other health professionals. Four (4) participants explained that they did see a social worker but they didn't benefit from it. Others experienced some form of relief. The following are some of the responses of the participants:

> **Participant 4**
> *"When the social worker visits us, they only talk to my mother as the patient and they never spoke to me. I also need their help, but they never engage with me. I am not aware of what are they exactly talking to her as they don't inform me at the end."*
>
> **Participant 9**
> *"I think social workers assisted me as they referred us for the application of the grant in aid for the person who is assisting him on a full-time basis. I was not aware of the information."*
>
> **Participant 11**
> *"It was difficult for me to cope with the situation during the start, but since I was referred to the social worker for counselling, I am now feeling better."*
>
> **Participant 6**
> *"Social workers attended to me with something else not concerning my son as patient. It was on the issue of my Identity document, and they couldn't reach the solution."*

Considering the experiences of participants, the assumption can be made that the multidisciplinary team for palliative care may experience challenges with a high patient load including the shortage of clinical social workers, psychologists and medical doctors. In general the shortage of health care professionals in the rural government hospital areas has a significant impact on service delivery to the terminal ill patients and their families.

2.11.3.2 Sub-theme 3.2: Medical doctor services

The role of the medical doctor is to inform the family about the patient's medical condition and explains the treatment recommendations, including expected benefits and side effects; explains what would happen without the treatment; and order tests, medication and treatments (Institute of Medicine, 2008:148). For most of the participants the medical doctor is an important member of the team attending to the terminally ill patient. The participants explained their experiences in this regard as follows:

> **Participant 10**
> *“Every time during the hospital visit, our main expectation is to see the doctor because we believe that is the only important service that we need.”*
> **Participant 5**
> *“Doctors always play an important role in the life of our loves ones as patients. During our hospital visits they check the patient for every disease like blood pressure, cholesterol, glucose level, body weight and height. This makes us to feel that doctors do care for the patients.”*
> **Participant 9**
> *“I think in the condition of my husband as he is seriously ill, he needs the attention of the doctor the most comparing to other professionals. After the doctor checked him, they prescribed medication that makes him to feel better.”*
> **Participant 6**
> *“The doctors plays a vital roles in the patient’s life. The doctors also asked as the questions concerning the patient during the hospital visit.”*
> **Participant 11**
> *“After we consulted with the doctor and the nurse, they are the ones who referred us to the rehab section for further assistance.”*

The participants reported that doctors are the most helpful health professional within the hospital team.

2.11.3.3 Sub-theme 3.3: Spiritual services

Saunders et al. (2010:50), indicate that many families and patients need help to face feelings of guilt and worthlessness that can truly be described as spiritual pain, sometimes amounting to deep anguish. Spiritual concerns need to be supported as much as physical and psychosocial issues in order to assist in recognising the purpose of meaning at the end of life.

Five (5) participants explained that fellow Christians visit them at home once a month and four (4) participants explained that they are affiliated with different churches but they never reported the sickness to the church. People who are coping with dying may seek to identify, recognise, or formulate meaning for their lives, for death, suffering and for being human (Corr et al., 2009:146). The participants explained that prayers from fellow Christians create some strength for them as family members. Two (2) participants are not affiliated with any church as they believe in their ancestors. When treating terminally ill patients, health care providers must acknowledge the spiritual dimension as an integral part of the dying process. The following are the responses of the participants:

> **Participant 2**
> *"I attend church services on Sunday at least twice a month and I believe that everything that's happening in my family it happen for a reason and God will help us."*
>
> **Participant 11**
> *"Since I am looking after my child I only attend a church service on Wednesday with a group of women. It encourages me to stay strong in life, though I'm facing difficulties.*
>
> **Participant 4**
> *"The church motivates me to remain positive in life and also to accept all the challenges in life."*
>
> **Participant 3**
> *"They also visit us here at home. During the day visit, they pray for us and encourage us to keep on praying and we must not lose hope."*

Participants reported that religion plays an important role in their lives by keeping them safe from the evil spirits that might cause danger to their families. The findings demonstrate that spiritual care may encourage the families to love and provide care to the terminally ill patients. Connectedness, illness and perhaps life threatening illnesses, threaten to break those connections that lend coherence to a person's life. It is important for a person in this situation to re-establish broken connections or to maintain and deepen existing connections. Transcendence refers to the ordinary things and especially to that which is of ultimate, surpassing worth (Corr et al., 2009:146).

2.11.3.4 Sub-theme 3.5: Psychological services

A recent report from the Institute of Medicine (2008:133) defines psychosocial health services as psychological and social services and interventions that enable patients, their families and health care providers to optimise biomedical health care and to manage the psychological, behavioural and social aspects of illness and its consequences so as to promote better health.

The research revealed that only two participants were seen by a psychologist. Nine (9) participants explained that they were never referred to a psychologist neither did they have any information about psychological services. Several government hospitals have a shortage of clinical psychologists especially in rural government hospitals with a high load of mental ill patients. Clinical psychologs are responsible for in and out patients which also increase their work load. Despite the latter, psychologists can provide an important psychosocial and behavioural health service to the terminally ill patients. The participants responded on this as follows:

> **Participant 4**
> *"I have seen by the psychologist only once as I was referred by the doctor after I was diagnosed with depression. I realized that their services were helpful. After the session I gained a lot of strength and it was easier to cope."*
>
> **Participant 5**
> *"I knew about psychological services before, but I didn't manage to go for consultations although there was a need for me."*
>
> **Participant 10**
> *"I was only informed that there are psychologists within the hospital and I wish I could make a consultation with them but I don't know about the procedure."*

Psychologists have many different roles in the management, treatment and study of chronic illness (Institute of Medicine, 2008:137). These include:

- **Health Service Provider**. Psychologists provide mental and behavioural health services to chronically ill patients (e.g., psychological assessment, intervention and consultation).
- **Teacher**. Psychologists provide education and training regarding the psychosocial influences of chronic illnesses on health, which helps patients develop better self-care and self-management skills to decrease the impact of the disease and prevent future health complications.
- **Researcher**. Psychologists conduct research and participate in studies on chronic illness that advance knowledge in the area of prevention, treatment and rehabilitation, which is essential to patients' successful management of their illness.

2.11.4 Theme 4: Types of services available within the community for the terminally ill patient and their families

A lack of institutional care, such as hospices, in rural areas of South Africa has been confirmed by the Department of Social Development (2010:8). It was indicated that only 5% of residential facilities in South Africa are in informal areas, while 16% in rural areas. This theme was divided into three sub-themes.

2.11.4.1 Sub-theme 4.1: Hospice rendering services

The WHO (2012:89) defines hospices care as a form of palliative care provided to patients who are expected to live six months or less and who are no longer receiving treatment for the cancer. The goal of hospice care is to help patients and their families cope with the physical and emotional impact of death and dying. Because many patients with advanced cancer continue to receive cancer treatments throughout the course of their illness, they may not be eligible for hospice care. The participants were asked whether hospice facilities for terminally ill patients are available within their communities. Ten (10) out of the 11 participants were not aware of such facilities except only one participant who was trained as a caregiver who was aware of such facilities. This participant reported that she was assisted by a hospice, while the rest of the participants did not receive any support from the hospice. The participants expressed their views as follows:

> **Participant 3**
> *“If I was supposed to make a choice, I will chose that my uncle to be admitted in the health facility. We are facing a huge challenge as he can`t even walk and is always asleep, whilst in the health facility they have their own ways on how to handle patients.”*
>
> **Participant 2**
> *“I think the hospice is the only relevant facility to handle the terminal ill patient not us at home. We are really struggling a lot.”*
>
> **Participant 1**
> *“Sometimes we are not doing good to the patient, as we are not trained to care for them.”*

> **Participant 9**
>
> *“I am struggling here at home as you can see I’m sick as well. He can’t walk, in case he has to take a bath I need to call another person to come and assist, and it makes him to be more aggressive towards me because I can’t even move him from point A to Z. I think if he can be accommodated in a health facility will simplify my life.”*
>
> **Participant 4**
>
> *“I will appreciate it if my mother can be admitted in such health facility, and that we as a family can visit her on a regular basis.”*

Some of the participants revealed that they would prefer the support of a hospice that could bring some form of relief when the patient becomes difficult and too sick to take care of at home. Participants were asked if they would prefer to care for their loved ones at home or at the health facility and all participants responded that they would consider the health care facility when it becomes a challenge at home to take care of the family member.

Different countries have different policies regarding hospice care for patients, and some countries do allow for cancer treatment and hospice care to be given at the same time. However, regardless of whether patients are eligible for hospice care while receiving cancer treatments, they can continue to receive palliative care services. Hospice services are often focused on providing the support needed for care at home, but both palliative and hospice services may be provided in a hospital or in a private care facility (WHO, 2012:98).

If the dying person has lived in the facility for a while, the staff and family have probably already established a relationship with each other. This can make caring for the patient feel more personalised than in a hospital as in a hospital, privacy can be an issue (WHO, 2012:201).

The researcher’s comment on palliative care is that hospice care is an end-of-life care provided by health professionals and volunteers. They provide medical, psychological and spiritual support with the goal of helping people who are dying, to experience peace, comfort and dignity. The caregivers in a hospice setting try to control pain and other symptoms so that a person can remain as alert and comfortable as possible. Hospice programs also provide support to the family of the patient.

2.11.4.2 Sub-theme 4.2: Support groups services

Hornillos and Crespo (2012:126) indicate that a support group refers to a mutual aid group and is one of the most widely used and popular interventions with family caregiving it has been identified as a basic form of psychosocial support for those families caring for terminally ill family members. Support groups also create an opportunity for the family caregivers to improve the condition in their environment and provide them with skills to manage a highly demanding situation to relieve their emotional distress, and maintain their quality of life (Social Tract, 2010: 51). Support groups have a variety of purposes and goals. They provide support, education, socialisation and self-help. Support enhances the family caregivers' sense of self-esteem and assertiveness. It assists the group members to vent strong feelings such as anger, regret and shame. Furthermore, support groups provide opportunities for family caregivers to learn powerful lessons about coping effectively with their family members with terminal illnesses. The majority of group members discover and improved the sense of interpersonal confidence and self-worth from sharing their experiences and expertise with fellow group members (Hornillos & Crespo, 2012: 137).

Some of the participants explained that they did attend support groups and indicated that it did added value to their lives. Other participants reported that they did not have enough time to attend a support group. Some stated that they did not know about the support group in the area where they lived. The participants responded as follows regarding their views about a support group:

> **Participant 5**
>
> *"By the time my husband was admitted at the hospital for the period of three months I used to attend the support group on a weekly basis. As we were sharing our challenges and experiences I felt relieved after wards. The support group was so helpful to me because it enables me to make some decision in my life."*

> **Participant 10**
> *"I attended a support group only twice, but because of other commitments I then failed. I have learned good lessons in the support group. There were a lot of things that I was not aware and when I became part of the group, I became more informed."*
>
> **Participant 3**
> *"I know nothing about support groups. No one ever explained to me on how support group works."*
>
> **Participant 9**
> *"It is very interesting in the support group meeting. The information is very helpful. I realised that I am not alone with this kind of problems, as others people's world are even worse."*
>
> **Participant 2**
> *"I wish to attend the support group. I use to attend during the past and I had good experiences concerning the support group. I have learned a lot. My problem is that I don't have money to travel to the hospital to attend the support group."*

The research findings revealed that the majority of the participants knew about the support groups. Two (2) of the participants reported that there was no support group in the area where they reside while two other stated that they were never informed about the support groups. Five (5) participants reported that they used to attend a support group in the past, but due to other commitments, they failed to keep it up. However, the majority of the participants agreed that attending support group meetings would be beneficial to them and their entire family. The research findings correlate with the literature of Social Tract (2010:83) which explains that a support group offers benefits to the family caregivers. Family caregivers gain experiences and learn from the different experiences of other caregivers. The group members also gain a better understanding of caring for their family members with terminal illnesses and increase their knowledge on community resources and support services. Families benefits also from the group especially regarding the way to deal with their feelings about caregiving, health concerns, obsessive thoughts, their changed social condition, fear, grief, and the way to deal with challenges, such as a lack of a support system, social isolation, and the way to reduce stress and to enhance one's coping skills. This is supported by Mundell (2013:178) who states that a support group provide opportunities to family caregivers to share their problems with other group members which in turn, prevent physical and emotional burnout.

2.11.4.3 Sub-theme 4.3: Community home-based care services

Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health, including care towards a dignified death (Borochowitz, 2011:42). The main aim of home-based care is to provide effective community-based care and support. Home care services can be classified into different categories namely: preventive, promote, therapeutic, rehabilitative, long-term maintenance, and palliative care. The WHO (1999:97) states that community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities. The WHO (1999:209) explains that the community home-based care programme promotes caregiving to individuals in their natural environment and in their homes (WHO, 1999:209). The target group for this programme is any person with a terminal illness or full-blown AIDS, and for chronically ill persons.

On a question whether the participants are receiving care and support from community home based care services, the majority of participants reported that they are receiving support from home-based care services. Six (6) participants explained that they are visited twice a month and four explained that they are visited once a month. Only one (1) participant stated that she was never visited by home-based carers. Ten (10) participants reported that the services offered by the home-based carers are very helpful in that they provide physical as well as spiritual support. Participants indicated that the support provided reduced some of their burden. The participants explained it as follows:

> **Participant 10**
> *"They visit my house twice a month, and assist me a lot as my husband is unable to walk, they also assist by taking him for a shower, cleaning and sometimes help me with cooking as well."*

> **Participant 3**
> *"Home based carers are very helpful to my family. After my uncle was discharged from the hospital it was a challenge to us as we didn't know where to start. The home based carers assist in bathing and feeding him."*
>
> **Participant 7**
> *"It was hard for me to accept the condition of my mother. As I am an elder sister and I have to look after my two siblings. But through the support from the community home based carers, it made it easier for me."*
>
> **Participant 5**
> *"They come every month, and provide even pampers. They educate me on TB, and showed me how best to provide a proper care to the patient."*

WHO (1999:227) contends that between 70% and 90% of illness care takes place within the home. Research evidence demonstrates that most people would rather be cared for at home and that effective home care improves quality of life for ill people and their family caregivers. Home based care is one of the best ways for most people to receive quality care. According to Russell and Schneider (2010:276), home-based care has become a national policy priority in South Africa as it helps those infected and affected with by HIV and AIDS and other terminal illnesses to cope better. Most importantly, it makes a significant contribution to relieve the burden of care resulting from HIV and AIDS on the health sector. In 2001 South Africa developed a national home based care strategy which resulted in the introduction of guidelines to operate home based care programmes. According to the Department of Health (DoH, 2001), due to the HIV and AIDS epidemic, the increase in non-communicable diseases and the complications of this diseases, it is necessary to plan how to care for people with diseases and their families.

The research findings show that home based care services are available in most of the community areas of the people with terminal illnesses. Such services provide support and care services to the families who are taking care to the terminally ill patients.

2.11.5 Theme 5: The challenges family members experience

According to the Institute of Medicine: Rare Diseases and Orphan Products (2010:26), caregivers in general face significant ethical challenges to their values and preferences for care at various transition points in the disease trajectory, for example, whether to participate in genetic testing, enrol in clinical trials, initiate mechanical ventilation, or withdraw therapies. Decisions of this nature, along with the overall strain of caring for a loved one, can lead to tension between the caregiver and the patient, as well as tension in family relationships, as they struggle between hope and cure and the eventual fatality. NORD (2015:52) explains that caregiver competence or perceived competence in caring for a loved one can affect the caregiver's quality of life. A caregiver's perceived competence can be affected by many related variables, like family income, their loved one's quality of life, and balancing the demands of other family members. The participants explained that they are not comfortable facing their family member`s eath at home, though it might be the wish of the patients to die at home. This theme is divided into three sub-themes.

2.11.5.1 Sub-theme 5.1: Challenges for children

Some of the participants explained that taking care of sick family members, affects the rest of the family system and may even lead to the decrease in the school performance of children in that specific families. Four (4) participants explained that the performance of their children decreased at school. They further explained that they were no longer enjoying their lives by playing with other kids. The participants responded as follows:

> **Participant 1**
> *"My first born child was negatively affected at school, and he failed twice in the same grade."*
>
> **Participant 11**
> *"My kids are no longer enjoying playing with other kids outside as compare to the past. They want to be with us always."*
>
> **Participant 5**
> *"Last time I was called at school concerning the performance of my son. I was told by the teachers that his concentration is poor and they wanted me to explain the reason behind it."*

According to Obe, Hanks, Cherny and Calman (2004:801) there are at least three views on how children acquire fears and anxieties:

- The psychoanalytic view suggests that anxieties and fears in children are derivatives of other anxieties and fears that develop in early life, principally separation anxiety, fear of object loss, fear of castration, fear of abandonment, and fears of physical immobility and darkness.
- The cognitive view relates to children's fears and anxieties about death to the stage of development and more about the concept of death. After the child develops the concept of the irreversibility of death, there will be a fear of its permanence.
- The social learning view puts forward the idea that children's ideas and feelings are influenced by their experiences and by the observations of others. The fear of death and anxieties in children will be influenced by their parents, as well as siblings, peers, teachers, and relatives. Siblings and peers can provide 'information' about death that can be truly frightening. The media (particularly television), children's books, and fairy tales have also been noted to be significant influences (Obe et al., 2004:801).

The findings of the study indicated that the terminal illness of a family member does not only affect the person who provides care to the family member, but the whole family, including children. As much as children are regarded as part of the family, counselling and psychosocial support have to be considered for them too.

2.11.5.2 Sub-theme 5.2: Challenges for family caregivers

Richter (2007:4) defines families as societal groups that are related by blood (kinship), marriage, adoption, or affiliation with close emotional attachments to each other that endure over time and go beyond a particular physical residence. Furthermore, a family is a group of two people or more (one of whom is the householder) related by birth, marriage, or adoption who live together (Belsey, 2005:11). One of the main functions of a family is to provide its members with love and affection. Peterson (2009:34) indicated that the role of the family is also to fulfil important functions for their members, such as membership, economic support, nurturance, socialisation and protection of vulnerable members. The findings are consistent with the views of Richter (2007:4) and Peterson (2009:34) in the above-mentioned statements. The participants explained that they are more attached to one another in the family. When one family member is sick it affects the whole family. Research proposed that family plays a significant role in the well-being of terminally ill family member (Gallagher-Allred, 2009:58). All participants reported that they are experiencing challenge in terms of family caregiving. The following responses are indicative of their experiences:

> **Participant 4**
> *"I have lots of challenges that I'm facing in this family. I don't have any support from relatives and I become too emotional when I look at my mother."*
>
> **Participant 5**
> *"I have financial challenges as I'm unemployed, and I can't go for a job and leaving my husband behind. So we rather suffer being together."*
>
> **Participant 1**
> *"I feel depressed as my social time now is very limited. I don't have time to visit my boyfriend and don't have time for my friends and going to church as usual."*

According to Peterson (2009:35), the above functions are also of importance when a family has to take responsibility for its family members in the case of palliative care, as they can be regarded as disabled and vulnerable, and society then has less responsibility towards the terminally ill patient.

The role and demands of family caregiving will depend on the setting of care such as caring for the patient at home versus in-patient units. These research findings correlate with the research of Stajduhar and Cohen (2009:98) who explain that caring for the terminally ill patient at home may be about the most intimate of basic needs, such as the physical aspects of care: giving baths, and helping them to eat, get dressed, use the bathroom, or even breathe. Whatever the specific tasks, hopefully it is a time of love and compassion and a time to resolve outstanding issues. Caregivers are also responsible for complex physical and medical care tasks including the assessment and management of symptoms, hygiene care, administration of medication, and consultation with health professionals (Hudson, 2009:88).

2.11.5.3 Sub-theme 5.3: Fears experienced by family members

In a study by Gallagher-Allred (2009:59), it is indicated that many patients are voicing their wish to die at home instead of in the hospital or in other health care institutions. Patients and family members often experience the fear of performing the task of taking care of terminally ill family members due to the uncertainty of what the future will hold and what to do when an unmanageable crisis develops and they are unable to obtain support. All participants explain that they have a fear concerning the health condition of the ill patients. They fear the unpredictability of their circumstance. Family members are often unable to tell the difference between a serious problems and a trivial one, and typically interpret small or large changes in the patients. They fear not knowing what to do in emergencies, or at the time of death. Furthermore, family members are often concerned about the impact taking care of terminally ill patients might have on other family members. The participants confirmed the latter through their responses as follows:

> **Participant 1**
> *"Since my mother is ill, I am in fear that what if she cannot make it and die. My siblings are still very young and it will be difficult for me to look after them as I'm not working."*
> **Participant 5**
> *"I have a fear for my kids because they love their dad very much. My fear is in case he dies they are going to be faced with serious problems as they are not going to see him anymore. With me, how can I explain to my kids that he is going to die?"*
> **Participant 4**
> *"My fear is as I don't have family now. My father passed on and my brother. What if my mother don't make it, it means I will be left alone with my kids. What makes my fear worse is that, relatives are not assisting even visiting us. It will be worse if my mother can die."*
> **Participant 11**
> *"As the doctor informed me that my child will not make it, it is just a matter of time. My fear is I won't cope in my life as I'm used to stay together with her. I don't know what will happen to me and my husband in case she passed on."*

The findings revealed that the majority of the participants experienced fear for the unknown concerning the medical condition of their loved ones.

2.11.6 Theme 6: Cultural factors to be considered during a terminal illness

The National Health and Medical Research Council (2011:46) states that decisions about patients and family members of those patients must always include the cultural or religious beliefs of the patients and their family members. The WHO (2012:158) supports the idea that patients and their families will need time to think about their goals and expectations in light of diagnosis and the expected disease course. According to Giger, Davidhizar and Fordham (2006:231), the adjustment and adaptation to a terminal illness are also related to a variety of cultural aspects, including race, gender, ethnicity, spiritual or religious beliefs, and sexual orientation. The concepts about the causes of terminal illness and reasons for various health conditions, values, and accepted ways of managing a condition are all cultural variables that determine attitude, adjustment, expectation and outcomes related to terminal illnesses. The majority of the participants considered their cultural beliefs and activities as critical. Participants also have different ideas of the causes of different types of terminal illnesses. This theme is divided into three sub-themes.

2.11.6.1 Sub-theme 6.1: Death as a taboo subject

In some cultures, talking openly about death and dying is not acceptable because it is considered disrespectful, bad luck, or as causing loss of hope (Giger et al., 2006:231). Many cultures actively protect dying family members from knowing their prognosis (Carteret, 2012:73). Cultural influences can significantly impact the patient's reaction to the dying process and the decisions the patient and the family make (Giger, et al., 2006:231 and Searight & Gafford, 2005a:335). The majority of participants explained that they consider death as not acceptable. The participants responded as follows:

> **Participant 5**
> *"I can see my husband is not going to survive because of HIV/AIDS. Lots of people died because of the illness. I think as people we lack discipline and respect and that is why we are dying in a large number."*

> **Participant 1**
> *"I have a serious challenge as my mother's condition becomes more complicated, I can see that she is going to die soon. At her age she was not supposed to die, because in our culture we only accept death if the person was old."*
>
> **Participant 10**
> *"I believe that only God knows if my husband will die or not. On my side I have done all what is needed in terms of taking care of him."*

The research findings showed that most family members do not discuss the issue of death, even if they realise the patient is dying or the doctor confirmed that the patient is not going to make it. They are occupied by death thoughts and the issue of death remains to their lives. The study further showed that the majority of the participants and their families beliefs that the death of someone cannot be decided or predicted by a human being, but rather believe that it is only God who makes the final decision.

2.11.6.2 Sub-theme 6.2: The use of traditional healing

The majority of the participants explained that they utilised traditional healers and indigenous medicine for their family members. The participants further explained that it never helped them. Some of the participants indicate that their ill family members and relatives insisted that they consult with traditional healers. They explained it as follows:

> **Participant 4**
> *"Sometimes it was a bit confusing to me if whether the illnesses need the attention of traditional healers or a medical doctor. At the beginning while my father was still alive, he took her for several times to the different traditional healers. It was getting better but after sometimes, her condition become worst."*
>
> **Participant 5**
> *"I don't believe much in the issues of culture and traditional healers, but my in-laws they do believe in them. They took my husband for several times to the traditional healers and instead his condition didn't improve."*
>
> **Participant 1**
> *"Before she was diagnosed with cancer and a brain tumour, we took her to a Sangoma who informed us that she has been witched at work. The Sangoma later gave us muthi and after a few days the condition complicated and that's where she was admitted for a long time in the hospital."*

Participant 2

"I don't believe on traditional healers that can cure the illness and I will not allow any family member to give Muthi or anything from traditional healers."

The use of Western medicine is generally acceptable to ethnically diverse patients in the care of terminal illness, although the level of acceptance depends on a number of factors (Giger et al., 2006:240 and Shavers, 2010:103). Alternative practices may be used simultaneously with Western medicine because of the perceived or real effectiveness of the treatments as experienced by the patient.

2.12 SUMMARY

The empirical results of the study that focused on the experiences of families regarding the caring for family members who are terminal ill were discussed in this chapter. The responses of the participants were analysed and substantiated with relevant literature.

The next chapter will focus on the conclusions and recommendations based on the research outcomes of this study.

3. CHAPTER 4: CONCLUSIONS AND RECOMMENDATIONS

3.1 INTRODUCTION

The final chapter summarises the research study and establishes if the research goal and objectives were attained. Conclusions emanating from the research study were drawn. Finally, recommendations are made for practice, policy, and further research in line with the themes and sub-themes of the study.

Terminal illness can be defined as a status assigned to a person who has been diagnosed with an illness and is expected to die within a certain time frame, usually six months (WHO, 2012:21). A terminal illness can also be referred to as an illness or injury that will inevitably result in the death of a patient. Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health, including care towards a dignified death (Borochowitz, 2011:42).

The researcher is of the opinion that there are challenges for families that have to deal with caring for family members who are terminally ill. Therefore, families need to be capacitated to be able to take care of their loved ones who are terminally ill. The researcher therefore did a qualitative study, which allowed her to explore the experiences of the families regarding caring for family members who are terminally ill.

The focus of this section is on the execution of the study, as well as how the goal and objectives of the study were achieved.

3.2 GOAL AND OBJECTIVES OF THE STUDY

The following objectives were pursued to accomplish the goal of the research study:

- To do a thorough literature study on family caregiving for a terminally ill patient, as well as the needs and challenges faced by family members while taking care of these patients at home.

- To explore the challenges family members are facing in taking care of terminally ill family members at home.
- To formulate recommendations based on the outcome of the study regarding support for family members that have to take care of terminally ill patients.

The goal of the study was to explore the experiences of families regarding caring for family members who are terminally ill at home, living in the community of Ehlanzeni District in the Mpumalanga Province. The way these objectives were operationalised during the study will be discussed in the following section and will be further confirmed by discussing the different conclusions.

3.2.1 Objective 1: To do a thorough literature study on family caregiving for a terminally ill patient, as well as the needs and challenges faced by family members while taking care of these patients at home

This objective was achieved through an in-depth literature review that was conducted to explore the experiences of family members who had to take care of terminally ill family members. The literature was presented in Chapter 2 of the research report and provided a thorough description of the key concepts, different medical conditions, diagnoses and palliative care. The literature review explored the concepts of terminal illness, patient, family, palliative care, death, and grief. Furthermore, the literature review was also focused on the impact of a terminal illness on a family system.

The literature review provided the researcher with a comprehensive understanding of the different experiences and challenges that can be faced by families regarding caring for terminally ill family members. This understanding formed a departure point for the empirical study.

3.2.2 Objective 2: To explore the challenges family members are facing in taking care of terminally ill family members at home

The objective was successfully achieved by the researcher by means of the empirical study. During the process, the researcher was able to explore the different challenges that were experienced by the family members whilst caring for family members who were terminally ill.

3.2.3 Objective 3: To formulate recommendations based on the outcome of the study regarding support for family members that have to take care of terminally ill patients

This objective was achieved and will be fully discussed in this chapter. Conclusions and recommendations for practice, policy, and future research are based on the research findings and conclusions were drawn concerning the experiences of families caring for family members at home who are terminally ill.

3.3 RESEARCH QUESTION

The following research question was utilised by the researcher to give direction during the study:

What are the experiences of families regarding caring for family members who are terminally ill living in Ehlanzeni District in the Mpumalanga Province?

The researcher managed to answer the research question based on the feedback that was received from the participants through the empirical study.

3.4 CONCLUSION

In conclusion, the theoretical framework for this study proved to be appropriate, as it helped the researcher to obtain a thorough understanding of the challenges and experiences of families caring for their loved ones with terminal illnesses. The study also explored the different experiences of families regarding caring for terminally ill family members at home. Furthermore, it also reveals the working relationship between the health care workers and the community home-based care services as a multidisciplinary team, the needs and challenges of the family members and patients, and the multidisciplinary team’s interaction with the families, health professionals, and the community services as part of the support system.

3.5 DISCUSSION OF KEY THEMES THAT EMERGED FROM THE EMPIRICAL FINDINGS

3.5.1 Theme 1: The family's understanding of the concept terminal illness

The study revealed that the family caregivers of the terminally ill patients often have insufficient knowledge concerning the terminal illnesses and the issue of palliative care in general. The data support literature that has shown that the population in developing areas had an insufficient and poor understanding of chronic diseases and terminal illnesses in general. It will be beneficial for the family caregivers to have sufficient knowledge concerning the terminal illnesses in order for them to cope with all the demands of caregiving and it will also decrease the level of burden.

The participant's view correlates with the recent research that describes the symptoms presented by terminally ill patients as follows: memory loss, severe diarrhoea, loss of appetite, loss of bladder or bowel control, drowsiness, and slow and noisy breathing.

It is the opinion of the researcher that the lack of health institutions, such as hospices, and the family caregivers' lack of knowledge about the patient's prognosis and the required medical treatment could contribute to the negative effects for both the patient and the family. The family caregiver can play an important role in the terminally ill family member's life if they are well informed concerning the patient's health condition and medication.

3.5.2 Theme 2: Effect of the terminal illness on the family system

The study revealed that all the caregivers of the terminally ill patients were related by blood to the patient, such as mothers, sisters, daughters, wives, and cousins. Literature emphasised that in many families, the caregiver is related to the patient by blood.

The empirical findings of the study revealed that the majority of the participants are negatively affected and are presenting with health concerns, such as general body pains, regular headaches, stress related illnesses, and fatigue, which are associated with the physical burden of caregiving. Most of the participants reported that they are already on chronic medication as a result of caring for to their terminally ill family member. The research findings correlate with the literature, which reported that the physical demands of caring for a family member with a terminal illness at home are often substantial and burdensome. This implies that caregiving has a significant effect on caregivers' well-being and their needs are frequently considered secondary to those of the patient, or are even completely overlooked. Some research has suggested that caregivers of people with cancer may have more unmet care needs than patients. In addition, families who are caring for terminally ill patients are exposed to unemployment and poverty-stricken conditions.

Despite the burden of family caregiving, the study revealed that family caregiving is also regarded as a symbol of love and care. Lambert, Harrison and Smith (2012:224) indicate that happiness over quality time spent with the patient, the ability to explore and resolve issues, and feelings of value and self-worth have all been reported by caregivers. In addition, it has been suggested that caring for the patient may help caregivers to accept the death of the patient and work through their grief (Lambert et al., 2012:230).

3.5.3 Theme 3: Role of health professionals in assisting terminally ill family members and their families

The social worker has a crucial role in improving the wellbeing and the quality of life of both terminally ill patients and their families, but the study revealed that some families did not have access to social workers and thus could not benefit from social work services. Considering the experiences of participants, the assumption can be made that the multidisciplinary team for palliative care may experience challenges with a high patient load, including a shortage of clinical social workers, psychologists, and medical doctors. In general, the shortage of health care professionals in the rural government hospital areas has a significant impact on service delivery to the terminally ill patients and their families.

Furthermore, literature revealed that the role of a doctor is to observe a patient’s medical condition and explain the treatment recommendations, including expected benefits and side effects; explain what would happen without the treatment; and to arrange for tests, medication, and treatments. The study also revealed that the main reason families visit a hospital is for their loved ones that can be examined by a doctor. For most of the participants the medical doctor is an important member of the team attending to the terminally ill patient. The study revealed that spiritual care is also a major motivational factor that enables families to cope with family caregiving challenges.

3.5.4 Theme 4: Types of services available within the community for the terminally ill patients and their families

The results of the study revealed that there are three types of services within the community, but only two that were active.

The first community service that the study revealed was support groups which provide support, education, socialisation, and self-help to the family caregivers of the terminally ill patients. Literature revealed that a support group enhances the family caregivers' sense of self-esteem and assertiveness (Hornillos & Crespo, 2012:137). The study revealed that through support groups, family caregivers gain experiences, learn from the different experiences of other caregivers, gain a better understanding of caring for their family members with terminal illnesses, and increase their knowledge on community resources and support services.

The literature revealed that the main aim of home-based care is to provide effective community-based care and support which can be classified into different categories, namely: preventive, promote, therapeutic, rehabilitative, long-term maintenance, and palliative care (Borochowitz, 2011:42).

3.5.5 Theme 5: The challenges family members experienced

The study revealed that family caregivers are not comfortable facing the death of their family members at home, even though it might be the wish of the patients to die at home. Participants expressed that their children react differently, with some showing a decrease in their school performance. The literature revealed that some of the challenges that affect family caregivers are as follows:

- Disturbed sleeping patterns
- Back, shoulder or neck pain
- Headaches and weight loss

- Fatigue and high blood pressure
- Depression and feelings of isolation

Peterson (2009:34) indicates that the role of the family is also to fulfil important functions for their members, such as membership, economic support, nurturance, socialisation, and the protection of vulnerable members. Richter (2007:4) defines families as societal groups that are related by blood (kinship), marriage, adoption, or affiliation with close emotional attachments to each other that endure over time and go beyond a particular physical residence. The findings are consistent with the views of Richter (2007:4) and Peterson (2009:34) in the above-mentioned statements. The participants expressed that they become more attached to other family members during the caregiving process. When one family member is sick, it affects the whole family. Research proposed that family plays a significant role in the well-being of terminally ill family members (Gallagher-Allred, 2009:58).

The research findings pointed out that stress and a lack of time to attend to personal needs are the main challenges faced by family caregivers. In the view of researcher, the government should ensure the availability of institutional care within rural areas. The study furthermore revealed that family caregiving has the potential to create an even stronger bond between the family members.

It became evident that two of the most prevalent stressors are the emotions displayed by family members and the ominous fear of the unknown. The study revealed that the emotions manifested by the terminally ill patient can have a profound and prolonged effect on the family members. Often, there is an increase in the caregivers’ anxiety as they are trying to cope with sadness and fear over the situation of the terminally ill family member.

3.5.6 Theme 6: Cultural factors to be considered during a terminal illness

It is important for health professionals to be familiar with the role of traditional healers and their practices. Traditional healers play an important role within the communities. Therefore, it must be included during the awareness campaigns concerning terminal illnesses. The study revealed that some of the participants utilised Western treatment options for their terminal ill family members.

There is a general view that it remains the responsibility of the government to engage with traditional healers and faith-based organisations to work together for the management of terminal illnesses.

3.6 RECOMMENDATIONS

The recommendations based on the findings of the study can help to improve the working conditions of health care professionals whilst providing care for terminally ill patients and their families. The following are the recommendations based on the conclusions, as formulated by the researcher:

- More studies need to be conducted on the different ways that health care workers, as part of a multi-disciplinary team, can provide support to family members when taking care of patients in the home setting.
- The unwillingness of certain cultural groups to participate in the study made it impossible to include them in the study, therefore more research needs to be done on this topic by including all cultural groups.
- It is recommended that extensive education must be provided to the traditional healers concerning the different types of terminal illnesses.

3.7 RECOMMENDATIONS FOR FURTHER RESEARCH

Based on the empirical findings of the study and the literature review, the following needs for further research were identified:

- A study focusing on caring for terminally ill patients at home will add value to the subject field. Further research should be conducted on male family caregivers and their understanding of their role in the family system. This type of study should explore their experiences in caring for both male and female terminally ill family members in order to make recommendations regarding what the needs and challenges are pertaining family caregiving.
- Further research should be conducted in urban areas. This type of study would indicate the different types of available community services being rendered to terminally ill patients and their families, as compared to the ones in rural areas. The findings of such a study will improve the quality of health care services.
- Furthermore, a study focusing on social workers should be conducted. In the researcher's opinion, this type of study could explore the perceptions of social

workers regarding social work services to terminally ill patients and their families, and their collaboration in a multi-disciplinary team that works alongside community services.

4. LIST OF REFERENCES

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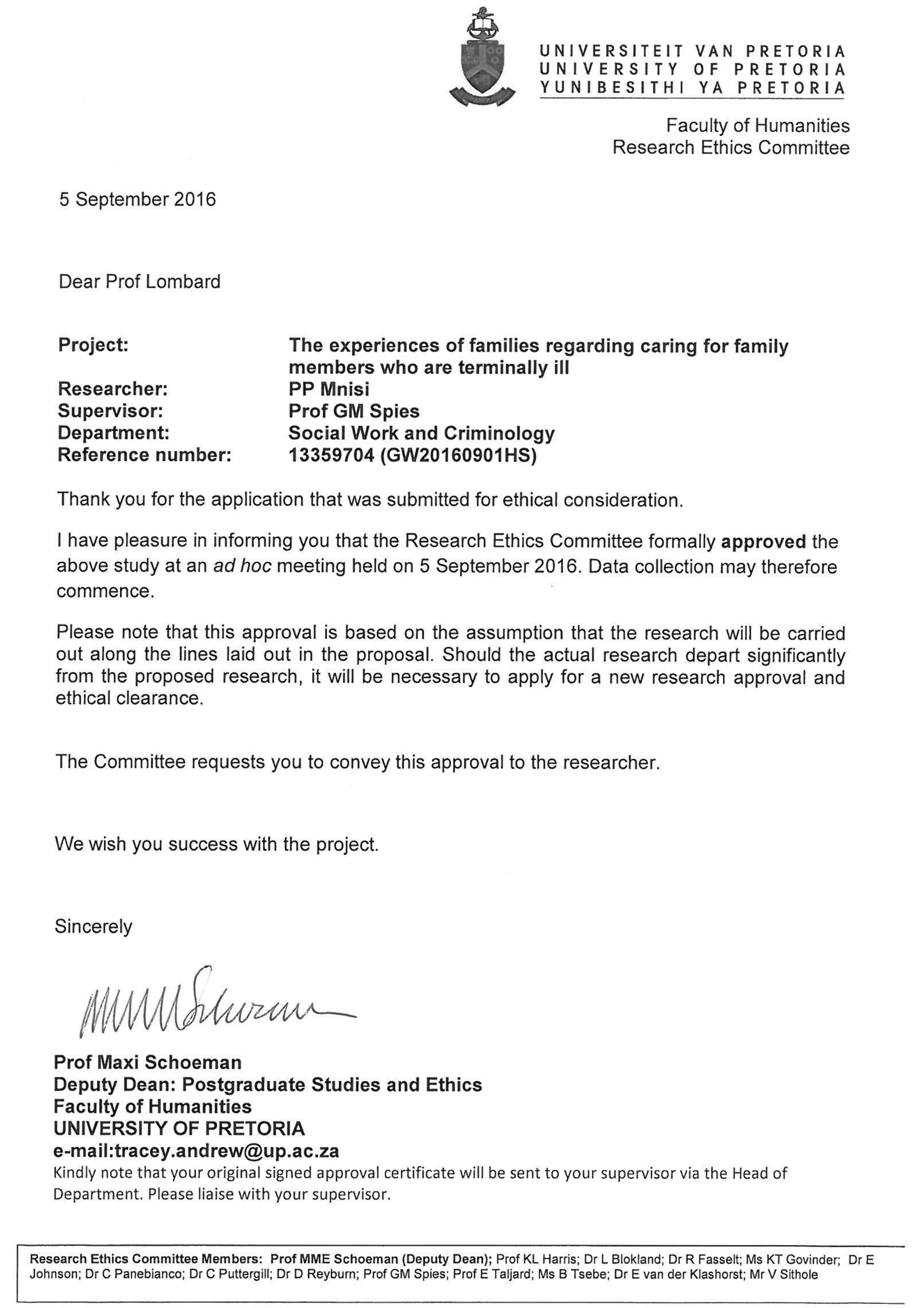
5. APPENDICES

5.1 APPENDIX A: ETHICAL CLEARANCE



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

5 September 2016

Dear Prof Lombard

Project:	**The experiences of families regarding caring for family members who are terminally ill**
Researcher:	**PP Mnisi**
Supervisor:	**Prof GM Spies**
Department:	**Social Work and Criminology**
Reference number:	**13359704 (GW20160901HS)**

Thank you for the application that was submitted for ethical consideration.

I have pleasure in informing you that the Research Ethics Committee formally **approved** the above study at an *ad hoc* meeting held on 5 September 2016. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

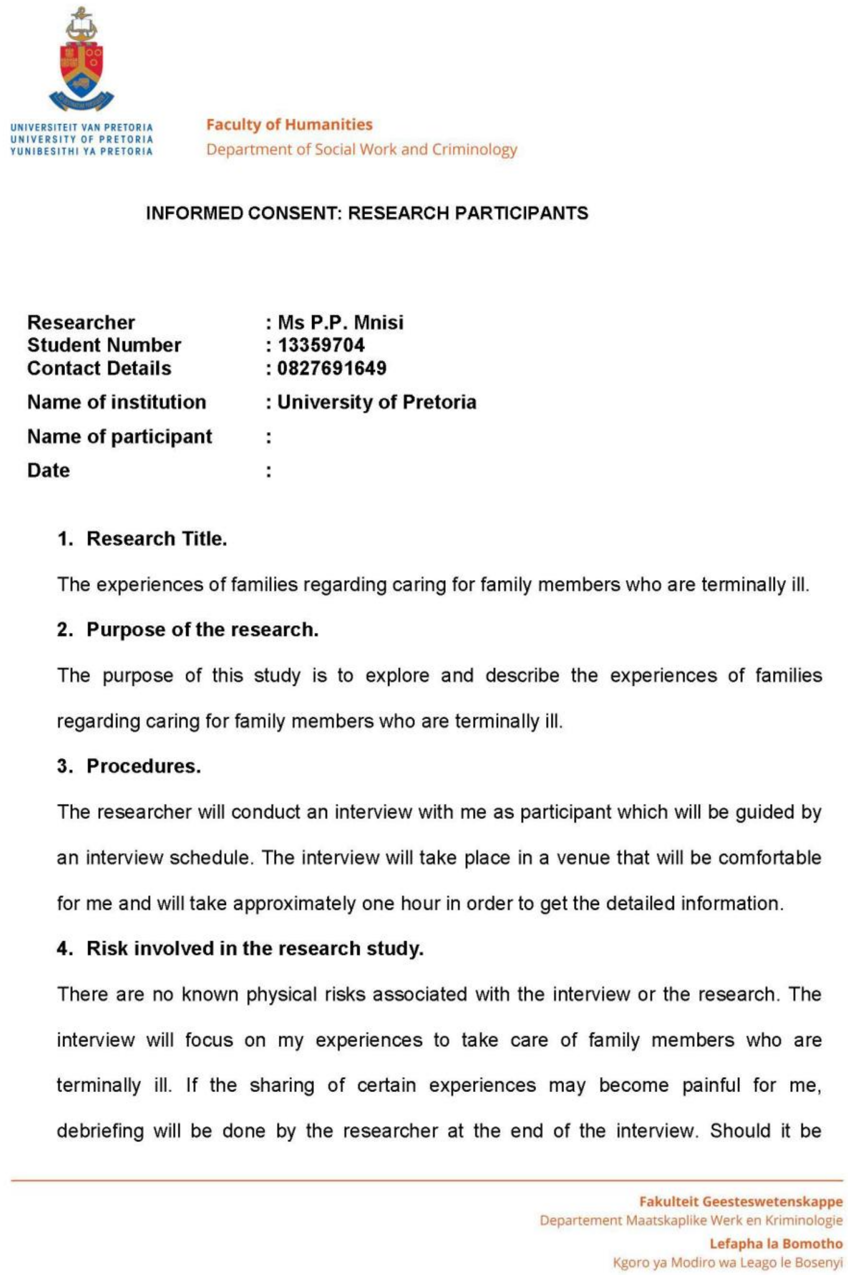
We wish you success with the project.

Sincerely

Prof Maxi Schoeman
Deputy Dean: Postgraduate Studies and Ethics
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail:tracey.andrew@up.ac.za

Kindly note that your original signed approval certificate will be sent to your supervisor via the Head of Department. Please liaise with your supervisor.

5.2 APPENDIX B: INFORMED CONSENT



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Faculty of Humanities
Department of Social Work and Criminology

INFORMED CONSENT: RESEARCH PARTICIPANTS

Researcher : Ms P.P. Mnisi
Student Number : 13359704
Contact Details : 0827691649

Name of institution : University of Pretoria

Name of participant :

Date :

1. **Research Title.**

The experiences of families regarding caring for family members who are terminally ill.

2. **Purpose of the research.**

The purpose of this study is to explore and describe the experiences of families regarding caring for family members who are terminally ill.

3. **Procedures.**

The researcher will conduct an interview with me as participant which will be guided by an interview schedule. The interview will take place in a venue that will be comfortable for me and will take approximately one hour in order to get the detailed information.

4. **Risk involved in the research study.**

There are no known physical risks associated with the interview or the research. The interview will focus on my experiences to take care of family members who are terminally ill. If the sharing of certain experiences may become painful for me, debriefing will be done by the researcher at the end of the interview. Should it be

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Departement Maatskaplike Werk en Kriminologie
Lefapha la Bomotho
Kgoro ya Modiro wa Leago le Bosenyi

necessary, counselling will be arranged for me by the researcher with a social worker at the hospital or within the community of Ehlanzeni district in Mpumalanga Province to attend to my needs in this regard.

5. **Benefits of the research study**.

I will not financially benefit from participation in the study as there will be no reward in cash or any other form of incentive. However, the outcome of this study may support me in taking care of terminally ill family members in the future.

6. **Voluntary participation**.

The participation in the research is voluntary and I have the right to decline or discontinue my participation at any time during the process if I choose to do so.

7. **Records of participation in this research study**

Information and responses provided by me will be kept safe and confidential in the Department of Social Work and Criminology at the University of Pretoria where it will be safely stored for 15 years. The interviews will be recorded and all people who will have access to the transcripts will be the researcher and her research supervisor at the University of Pretoria. The results of this research may appear in a professional journal or presented at a professional conference or be utilized for references in future research.

8. **Contact person.**

For more information regarding this research or any other concern, I can contact the researcher on the following number: Ms Pertunia Mnisi at: 076 1531 040 (office hour) 013 756 6300 (ext 6355).

9. **Agreement to participate in the research study.**

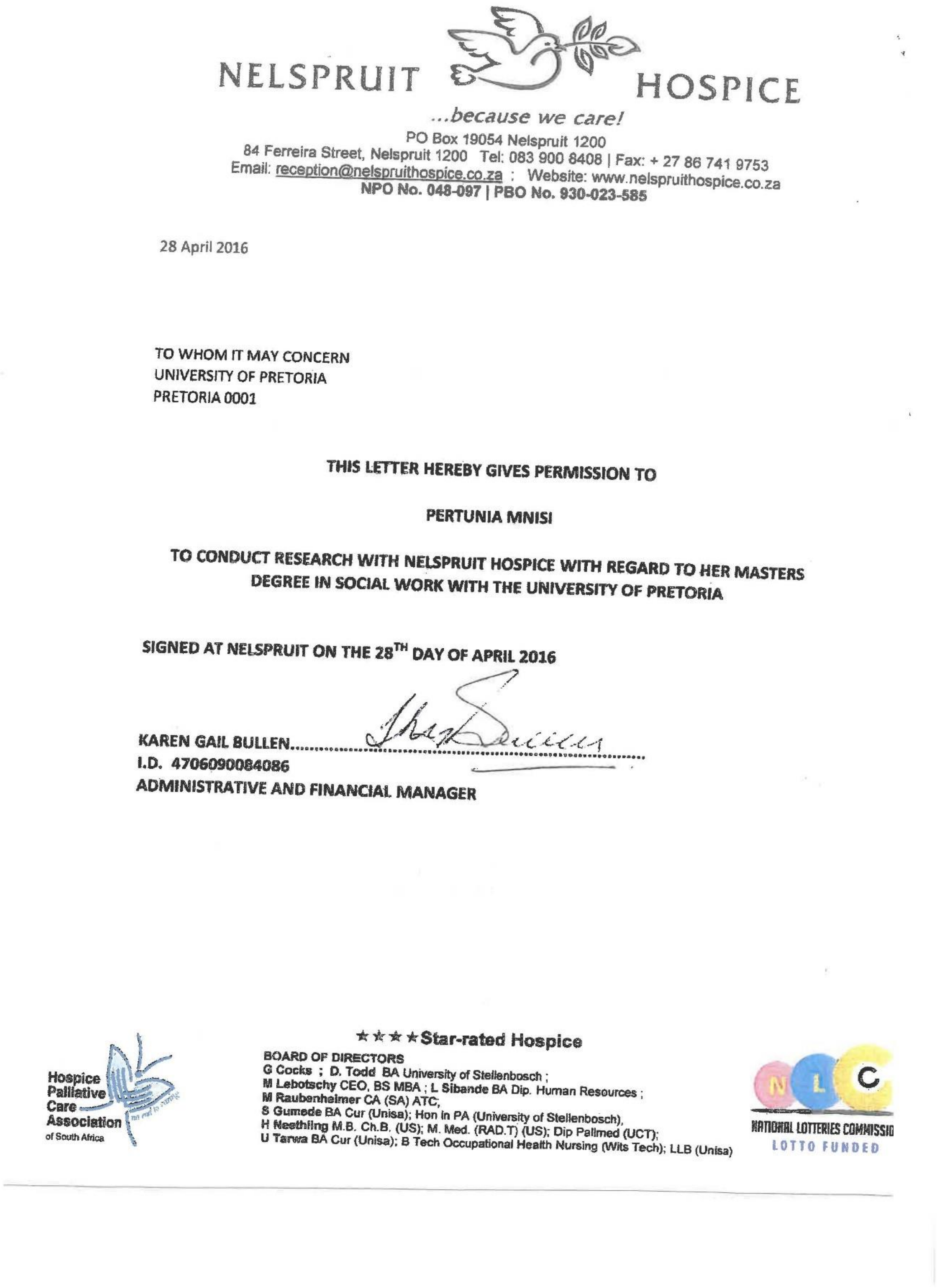
I __________________________have read and understood the information provided at the above and all my questions and concerns were clarified to my satisfaction. I have freely agreed to participate in this research study.

Signed at _________________ on the ______ day of ___________2016.

Signature of the participant: _______________________

Signature of the researcher: _______________________

5.3 ANNEXURE C: LETTER NELSPRUIT HOSPICE



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NPO No. 048-097 | PBO No. 930-023-585

28 April 2016

TO WHOM IT MAY CONCERN
UNIVERSITY OF PRETORIA
PRETORIA 0001

THIS LETTER HEREBY GIVES PERMISSION TO

PERTUNIA MNISI

TO CONDUCT RESEARCH WITH NELSPRUIT HOSPICE WITH REGARD TO HER MASTERS DEGREE IN SOCIAL WORK WITH THE UNIVERSITY OF PRETORIA

SIGNED AT NELSPRUIT ON THE 28TH DAY OF APRIL 2016

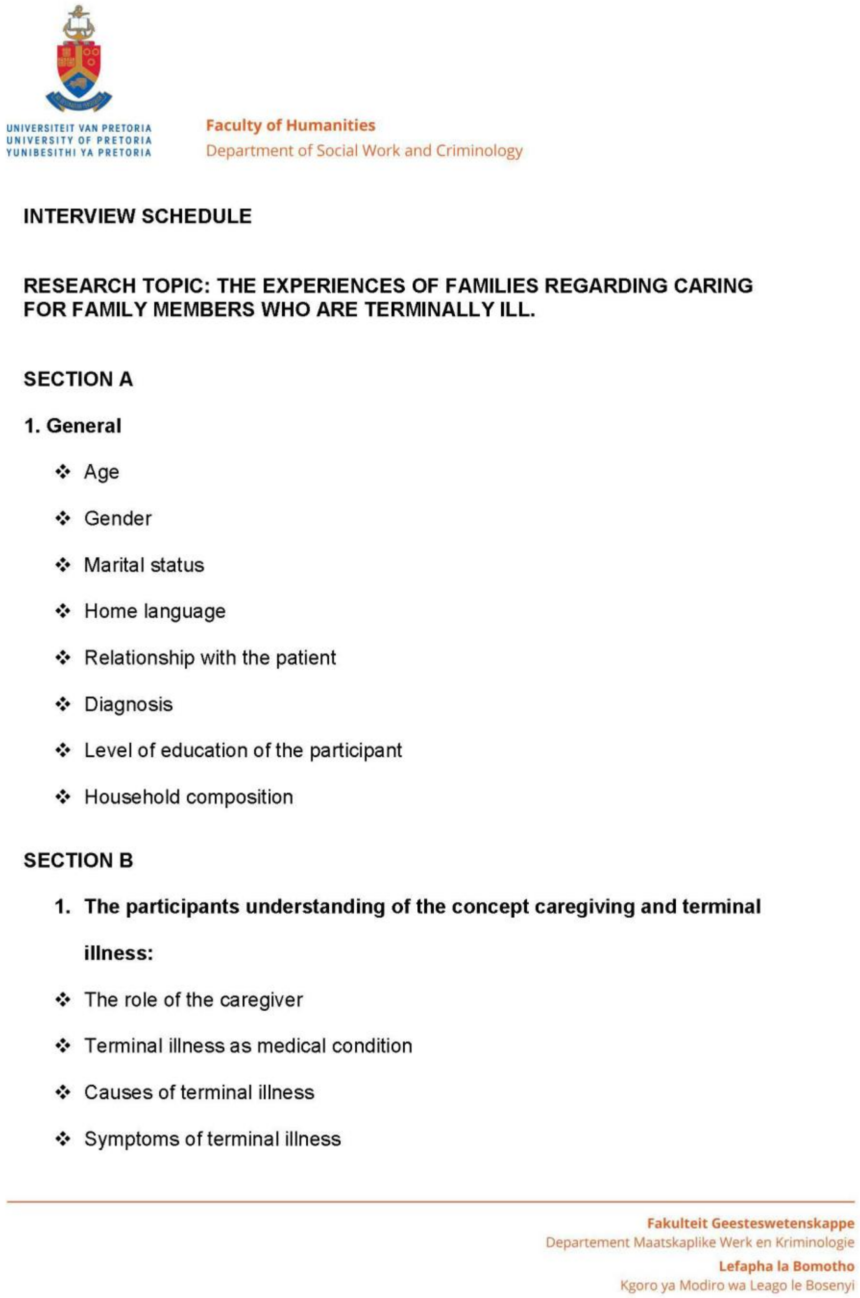
KAREN GAIL BULLEN...
I.D. 4706090084086
ADMINISTRATIVE AND FINANCIAL MANAGER

Hospice Palliative Care Association of South Africa

★★★★ **Star-rated Hospice**

NLC
NATIONAL LOTTERIES COMMISSIO
LOTTO FUNDED

5.4 APPENDIX D: INTERVIEW SCHEDULE



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Faculty of Humanities
Department of Social Work and Criminology

INTERVIEW SCHEDULE

RESEARCH TOPIC: THE EXPERIENCES OF FAMILIES REGARDING CARING FOR FAMILY MEMBERS WHO ARE TERMINALLY ILL.

SECTION A

1. General

- Age
- Gender
- Marital status
- Home language
- Relationship with the patient
- Diagnosis
- Level of education of the participant
- Household composition

SECTION B

1. The participants understanding of the concept caregiving and terminal illness:

- The role of the caregiver
- Terminal illness as medical condition
- Causes of terminal illness
- Symptoms of terminal illness

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Lefapha la Bomotho
Kgoro ya Modiro wa Leago le Bosenyi

- Treatment of terminal illness
- Prognosis of terminal illness

2. Effect of caregiving on the terminal ill family member

The views of the participants regarding the effect of caregiving on the life of the terminal ill family member:

2.1 Effect of caregiving on the physical wellbeing of the terminally ill family member.

- Describe the effect of caregiving on the physical well-being of the terminally ill family member

2.2 Effect of caregiving on the psychological wellbeing of the terminally ill family member.

- Frustration and loneliness
- Dependence on others
- Financial concerns
- Stress
- Depression
- Fear

2.3 Effect of caregiving on the social functioning of the terminally ill family member.

- Social isolation
- Lack of social support
- Role conflict

- Loss of social interaction

3. The support of services in the community

The views of participants regarding the following services in the community:

3.1 Health care services

- The quality of health care services
- Accessibility of health care services
- Attitude of health care professionals
- Diagnosis and treatment received from health care services

3.2 Home based care services

- Accessibility of home based care services
- The quality of home based care services
- Utilisation of home based care services

3.3 Respite care

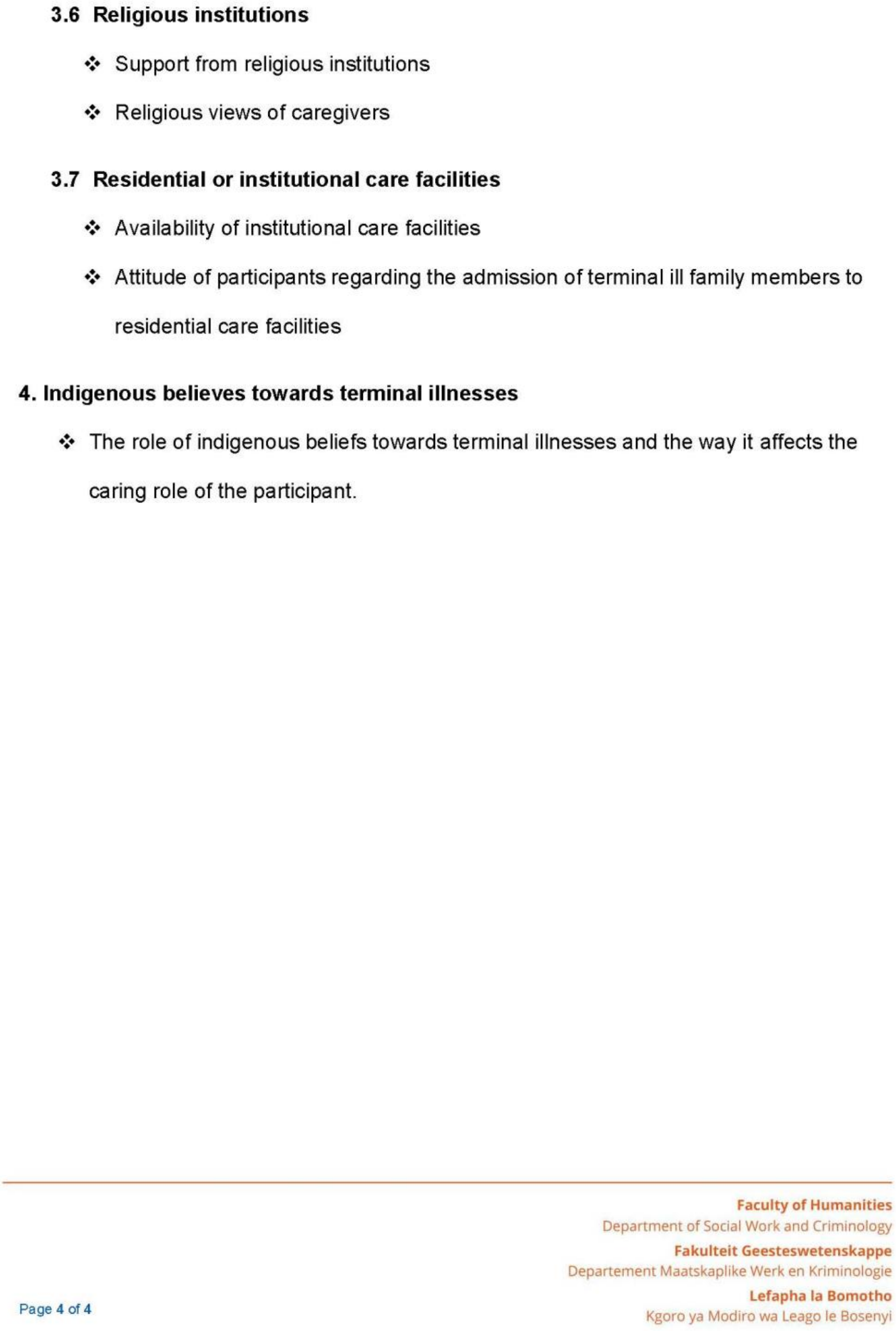
- Accessibility of respite care services
- The quality of respite care services

3.4 Support group

- Availability of support groups
- Accessibility of support groups
- The value of support groups

3.5 Social work services

- Accessibility to social work services
- The value of social work services



3.6 Religious institutions

- Support from religious institutions
- Religious views of caregivers

3.7 Residential or institutional care facilities

- Availability of institutional care facilities
- Attitude of participants regarding the admission of terminal ill family members to residential care facilities

4. Indigenous believes towards terminal illnesses

- The role of indigenous beliefs towards terminal illnesses and the way it affects the caring role of the participant.