Exploring palliative caregivers’ experiences of compassion fatigue in a hospice

by

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DECLARATION

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I hereby declare that “Exploring palliative caregivers’ experiences of compassion fatigue in a hospice” is my own work and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

___________________________                   February 2016
Boitumelo Maja                          Date
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ABSTRACT

Caring for the chronically ill is a growing phenomenon that deserves careful attention and research, since the quality of life of the palliative caregiver is threatened by the continuous exposure to psychological, physiological, as well as relational burdens. A hermeneutic phenomenological study was used to explore palliative caregivers’ experiences of compassion fatigue when caring for chronically ill patients in a hospice setting. Semi-structured interviews were conducted with Bophelong Community Care Centre’s palliative caregivers between the ages of 20 and 60 years who were employed in a hospice for a minimum of at least two years, thus well-placed to describe their experiences of compassion fatigue when caring for chronically ill patients in a hospice setting. Data was collected through individual interviews, recorded and transcribed. Using thematic analysis, meaningful patterns and themes of data were discovered to better understand compassion fatigue as a phenomenon of interest. The findings pointed to four categories, i.e. the effects of compassion fatigue on palliative caregivers’ emotional wellbeing, personal and work relationships, physical discomfort, and spiritual awareness, that describe the experiences of palliative caregivers of compassion fatigue in a hospice setting, thus providing a holistic understanding of the complexity of compassion fatigue in a palliative care hospice setting.

**Keywords:** Caregivers, chronically ill patients, compassion fatigue, hospice, palliative care.
LIST OF ABBREVIATIONS

ARP - Accelerated Program for Compassion Fatigue
ASD - Acute Stress Disorder
CF - Compassion Fatigue
HPCA - Hospice Palliative Care Association of South Africa
NGO(s) - Non-governmental organisation(s)
PTSD - Post-Traumatic Stress Disorder
STS - Secondary Traumatic Stress
STSD - Secondary Traumatic Stress Disorder
UNISA - University of South Africa
VT - Vicarious Trauma
WHO - World Health Organization
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CHAPTER 1

ORIENTATION OF THE STUDY

1.1 INTRODUCTION

There is a growing interest in the literature that describes compassion fatigue (CF) in various helping occupations. Research has shown that those who help people who have been exposed to traumatic stressors are at risk of developing negative symptoms associated with burnout, depression, and Post-Traumatic Stress Disorder (PTSD) (Stamm, 2010). It is through the concept of helping and providing care for the terminally ill that the phenomenon of compassion fatigue was brought to the attention by the nursing, healthcare society as well as the palliative care society.

Palliative care is defined as the total care of people who are dying from active, progressive diseases or other conditions when curative or disease-modifying treatment has no more effect on the patient’s disease or illness, therefore creating awareness for total care where mind and body are linked (Hughes, Van Heugten, & Keeling, 2015). This approach to palliative caregiving has shifted the emphasis from physical care to total care, referred to as a holistic approach to caring (Hughes et al., 2015). The World Health Organization (WHO, 2006), on the other hand, has a more universal definition of palliative care: it is defined as an approach that provides effective relief from pain and other symptoms, affirms life and regards death as a normal process, offers support to help people live as actively as possible right up to their deaths. The WHO further asserts that palliative care integrates psychological and spiritual care, provides support to family carers and helps families to cope with patients’ illness and bereavement, and also to provide support to professional care-givers.
For the purpose of this study, Hughes et al.’s (2015) definition was applied, as it took on a range of factors that goes beyond the physical discomfort to the cognitive and emotional discomfort (Hughes et al., 2015). The factors that the researcher was interested in are the physical, social, spiritual and psychological, as factors that influence the perception of pain and discomfort.

According to Sabo (2008), palliative care practice has its roots in care and caring and it is aimed at the prevention and relief of suffering, while physically, psychologically and spiritually enhancing the quality of the caregivers’ lives. The prevalence of compassion fatigue has been reported among professional caregivers, such as nurses, doctors, counsellors, social workers, and victims of war (Coetzee & Klopper, 2010; Figley, 1995; Hughes et al., 2015; Joinson, 1992; Leiter & Spence Laschinger, 2006). Therefore, palliative care represents a holistic care of terminally ill patients in diverse services, from medical treatment to patient support.

When a person is dying or chronically ill, attention is more often focused not only on the physical, but also on the spiritual, financial and psychosocial needs of the patients and their families (Woods, Craig, & Dereng, 2005). Some of the challenges faced by palliative caregivers are increased demands and emotional burdens of caring and providing around-the-clock physical, spiritual and emotional support. Ferrans (1990) reported that providing care for patients who are chronically ill and near the end of life can generate significant work-related stress, that can result in employee work dissatisfaction and mental exhaustion (Ferrans, 1990).
Evidence highlighted three concepts that are most frequently associated with the adverse consequences of the palliative caregiver’s work: compassion fatigue (secondary traumatic stress), burnout and vicarious trauma (Figley, 1995; Leiter & Spence Laschinger, 2006; Pearlman & MacIan, 1995). According to Munroe (1995), compassion fatigue (CF), burnout, vicarious trauma (VT) and secondary traumatic stress (STS) are used interchangeably and are all associated with the cost of caring. Although these phenomena are used interchangeably, compassion fatigue has become the cornerstone in the vocabulary of describing the negative effects that are experienced by the caregivers. The caregivers become preoccupied with their patients’ suffering and they experience even more intense urges to help, without realizing that they are in fact being affected by their patients’ pain and suffering.

This research project explored palliative caregivers’ experiences of compassion fatigue within the Tshwane District in South Africa, with a specific focus on the Hospice at the Bophelong Community Care Centre in Mamelodi. Ultimately, the aim of this research was to explore palliative caregivers’ experiences of their physical, psychological, spiritual, emotional and relational dimensions of compassion fatigue.

Compassion fatigue has been identified in the literature as issues influencing the cognitive, affective, social, spiritual, physical, and behavioural experiences of helping professionals (Robinson, 2005). The helping professionals may struggle with the balance of being helpers and being in the shadow of their patients’ experiences, and this can put a strain on the carers’ spiritual and emotional ability to cope with their daily witnessing of trauma and its effect.
This study focused on the palliative caregivers’ experiences when caring for terminally ill and near end-of-life patients. The phenomenon that was explored is compassion fatigue within the palliative care services at Bophelong Hospice in the Tshwane District of South Africa. While there are many rewards for some palliative caregivers in working with traumatized, terminally ill and near end-of-life patients, Pearlman and Saakvitne (1995), however, assert that compassion fatigue refers specifically to the negative aspects experienced by the palliative caregivers.

This chapter briefly outlined the statement of the problem, the aim of the study, the research question, a definition of operational concepts, the purpose and significance of the study, literature review, theoretical framework, research design, research participants, data collection procedures, data analysis, ethical issues, trustworthiness, assumptions of the study, and the schedule as well as the costing of the study.

1.2 RESEARCH PROBLEM

A number of studies have been conducted on the experience of compassion fatigue (Coetzee & Klopper, 2010; Edwards & Karnilowicz, 2013; Lawson, 2008; Lawson, Bodenhorn, Fazio-Griffith, & Skaggs, 2009; Perry, Dalton, & Edwards, 2010; Potter, Deshields, Divanbeigi, Berger, Cipriano, Norris, & Olsen, 2010); however, little research has been done within the South African context (Coetzee & Klopper, 2010; Harinarain, 2007; Uren, 2009). The studies were conducted in Canada (Perry et al., 2010; Sabo, 2008; Woods, 2011) and in the United States (Dogbey, 2008; Gentry, 2002; Palomino, 2008; Parker, 2009; Robinson, 2005) on palliative caregivers and their experiences of compassion fatigue. The researcher is of the opinion that there might be contextual factors in South Africa that differ from those in developed countries, such as
Canada and the United States; therefore the researcher feels that the findings from the context of developing countries, such as South Africa, may yield distinctly different findings than those from research done in Canada and the United States.

The concept of compassion fatigue was first used to describe the prevalent experience among professionals such as nurses, physicians and counsellors (Joinson, 1992). Research by Potter et al. (2010) indicates that compassion fatigue can take a toll on the caregiving profession as well, and as palliative care is an approach that provides effective relief from pain and other symptoms, and also affirms life (WHO, 2006), palliative caregivers fall within the professions that are mentioned by Joinson (1992). While compassion fatigue has been studied extensively within the family caregiving context, counselling and nursing environment, there is a need for further research on how palliative caregivers experience the phenomenon within a hospice setting.

More recent studies explored compassion fatigue as experienced by family members caring for their loved ones (Day & Anderson, 2011; Palomino, 2008; Parker, 2009; Perry et al., 2010). Other research focused more on the nurses’ experiences (Coetzee & Klopper, 2010). Research shows that South Africa is faced with the challenges of infectious diseases, poverty-related conditions such as HIV and Aids, nutrition deficiency diseases and tuberculosis (TB), chronic lifestyle diseases as well as health issues resulting from trauma and injuries (Solomon, 2014; Van Rensburg, 2004). South Africa continues to face a number of challenges with regard to having the largest HIV and Aids burden, cancer and opportunistic infections such as TB being most prevalent (Connor & Sisimayi, 2013), straining the palliative care services (United Nations, 2008). Palliative care, in a form of home-based care and community care, was established by the South African Government.
as the backbone of providing accessible care for terminally ill patients (United Nations, 2008). Aggravated by the high poverty rate, where more than half (54%) of South Africans live below the poverty line (27 million people living on R779,00 or less per month), community- and home-based care has proven to be the most effective human capital promotion in South Africa (Statistics SA, 2015; Uren, 2009). South Africa has a long history of community participation and mobilisation, which has influenced the community caregiver programmes post-1994 (Connor & Sisimayi, 2013).

In South Africa, palliative care should be considered a much higher priority based on the increase of terminal illness, and more structured palliative care training, mentorship programmes and ongoing support will strengthen the palliative care system in South Africa. Therefore, the researcher argues, the poor presence of palliative care could be largely related to the need for training that is carefully tailored to palliative care in the South African context (Uren, 2009). The knowledge derived from palliative caregivers’ experiences of compassion fatigue will enable the structuring of training and mentorship programmes that will be effective in enhancing the knowledge and skills of palliative caregivers in South Africa.

Previous research has maintained a predominantly quantitative focus with regard to the emotional experience of compassion fatigue on caregivers, the level at which compassion fatigue is experienced and its prevalence in a hospice setting (Abendroth & Flannery, 2006; Leiter, Harvie, & Frizzell, 1998). However, there is a need for a qualitative study that will enable the researcher to explore compassion fatigue to facilitate an in-depth understanding of the phenomenon as well as enabling the consideration of subjective accounts and
experiences of compassion fatigue by caregivers within the South African context (Whitley, 2002).

Literature suggests that compassion fatigue can result in symptoms that can potentially disrupt, destroy, or dissolve the palliative caregivers’ careers as well as their families and lives (Gentry, 2002). Because the concept of compassion fatigue has evolved from the concept of PTSD and Acute Stress Disorder (ASD) within the field of traumatology (Collins & Long, 2003; Figley, 1995), as an occupational stress syndrome it is important not only to try to understand how compassion fatigue manifests itself, or how it can be measured as a variable, but rather to be more concerned with the meaning that palliative caregivers ascribe to the concept of compassion fatigue as a phenomenon that can be experienced differently by each palliative caregiver. It may be of benefit to the design of palliative care training and programmes and how they are implemented. The findings may also give an indication of the important issues that alter the palliative caregivers’ abilities to provide effective palliative care.

1.3  AIM OF THE STUDY

The aim of this study was to explore palliative caregivers’ experiences of their physical, psychological, spiritual, emotional and relational dimensions of compassion fatigue in the context of a hospice.

1.4  RESEARCH QUESTION

The primary research question for this study is: What are the experiences of palliative caregivers of compassion fatigue within the Bophelong Hospice in the Tshwane District?
Definition of operational concepts

Analysing the literature on the phenomenon of compassion fatigue, the later distinguishable concepts of palliative care, compassion fatigue, burnout, hospice and caregiving have been commonly used by many researchers and studies to further understand the experiences of compassion fatigue as experienced by palliative caregivers (Figley, 1995; McCann & Pearlman, 1990; Papalia, Stern, Feldman, & Camp, 2002; WHO, 2006).

Palliative care is defined as an approach that provides a holistic care for terminally ill and near end-of-life patients. It affirms life, relieves pain and helps family with bereavement (WHO, 2006).

Compassion fatigue is defined by Figley (1995) as a secondary traumatic stress reaction resulting from helping or desiring to help a person suffering from traumatic events. Caregivers experiencing compassion fatigue may develop a preoccupation with their patients by re-experiencing their trauma, and may exhibit symptoms of avoidance of reminders, numbing in response to reminders, anxiety, and persistent arousal.

Burnouts are defined as feelings associated with hopelessness and difficulties in dealing with work or doing the work effectively, and these feelings usually have a gradual onset and may be the result of a high workload or a non-supportive environment (McCann & Pearlman, 1990).

A hospice is an institution that differs from a hospital setting, where there is a particular focus on the terminally ill and those who need around-the-clock medical care, assistance
and pain management (Papalia et al., 2002). Caregiving is regarded by Gentry (2002) as an informal care of individuals whose physical, mental, emotional or economic independence is limited.

1.5 PURPOSE AND SIGNIFICANCE OF THE STUDY

Compassion fatigue was first introduced by Joinson (1992) while investigating the nature of burnout in nurses in an emergency department, and she noticed that nurses in the unit seemed to have lost their “ability to nurture” (p.118). Joinson never formally defined the concept until 1995, when Figley defined it as a more “user-friendly term” for secondary traumatic stress disorder (STSD) (Figley, 1995). An enhanced understanding and knowledge of the palliative caregivers’ experiences in dealing not only with compassion fatigue but also burnout, vicarious trauma, the effect of death and bereavement and how they deal with the situation on a daily basis, will bring to the fore the unique dimensions that are involved in both caregiving and helping professions.

These unique dimensions may ensure that palliative care service is improved, provide organisations with evidence to develop interventions to maintain optimal working environments, and employees’ wellbeing is prioritised, as compassion fatigue will affect the caregivers’ nurturing ability negatively. Professional growth and development start with compassion, patience and support (Joinson, 1992).

The purpose of this study was therefore to reveal a deeper knowledge of compassion fatigue through the palliative caregivers’ experiences. Gaining a better understanding of the extent to which palliative caregivers and other healthcare providers are affected by conditions such as burnout and compassion fatigue is critical for the development of a
positive and nurturing working environment. The study may be the first step towards the ultimate design of comprehensive programmes and ongoing interventions to better equip and give support to palliative caregivers in order for them to recognise and manage compassion fatigue and burnout (Potter et al., 2010). It was indicated by Potter et al. (2010) that caring for patients and loved ones in an appropriate way is a skill that needs to be developed, making it important for palliative care training and development to have insight into the experiences of palliative caregivers of compassion fatigue.

Caring for the chronically ill is a growing phenomenon that deserves careful attention and systematic research, since the quality of life of the caregiver is threatened by the continuous exposure to psychological, physiological as well as relational burdens (Epstein, Baldwin,& Bishop, 1983). This study will add to a better understanding of compassion fatigue as experienced by palliative caregivers, which may also contribute to the Hospice Palliative Care Association of South Africa (HPCA, 2011) with its transition plan in the mentorship and provincial training plans to strengthen palliative care.

1.6 ASSUMPTIONS OF THE STUDY

It is assumed that the participants in this study experienced compassion fatigue and they were truthful and honest about their experiences when caring for chronically ill patients.

1.7 STRUCTURE OF THE STUDY

Chapter 1 provided an outline of the study. Chapter 2 focused on a literature review with regard to palliative caregiving, compassion fatigue and secondary trauma, with particular reference to the South African context.
Chapter 3 described the research methods that will be used in this study, the participants and the ethical considerations as well as the method of data analysing. Chapter 4 presented the findings of the research, and interpreting those findings, while Chapter 5 will deal with recommendations and suggestions for further research.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter contains a review of research literature related to palliative caregivers’ experiences of compassion fatigue while caring for chronically ill patients.

For this literature study, the term caregivers was used to refer to professional caregivers such as nurses, social workers, doctors, hospice caregivers, and home caregivers. However, palliative caregivers were the subjects of focus in this study. All the above professional caregivers are selected due to the limited literature that is available on palliative caregivers within these professions, their characteristics and their experiences, as well as their exposure to their clients’ or patients’ trauma.

The first component of this literature review was to describe of palliative care and compassion fatigue, and the association of compassion fatigue and burnout in a hospice setting. Secondly, the ecological model as a contributing framework used for the understanding of the dynamics of caregiving for the chronically ill will be researched. Finally, this literature review presented an overview of research literature addressing the impact of chronic illness on the mental, physical, social, and psychological aspects of the primary caregiver in a hospice setting.
Compassion fatigue encompasses psychological symptoms that are the result of an extreme emotional event caused by the exposure to others’ pain and suffering. It has been suggested by Herman (1997) and Pearlman and Saakvitne (1995) that therapists, caregivers and medical practitioners sometimes experience countertransference reactions that imitate the symptoms of their clients. There are many rewards reported for caring for chronically ill patients, such as facilitating involvement and bringing closeness between the caregiver and the patients. However, there are also detrimental effects on the caregivers’ quality of life (Gentry, 2012; Giles, 2011; Goldman, 2002).

Palomino (2008) aimed to identify and describe the experience of caregivers caring for chronically ill patients and its multiple impacts on the caregivers, and what he found was that caregiving for chronically ill patients has negative effects on the lives of the caregivers in various areas, therefore causing emotional burnout and impacting negatively on family relationships. Palomino’s (2008) findings support Figley (2002) on the notion that being compassionate and empathetic involves costs in addition to the energy required to provide the necessary care and service.

### 2.2 CONCEPTUALISATION OF COMPASSION FATIGUE

The very act of being compassionate and empathetic extracts a cost under most circumstances (Figley, 2002). The caregivers’ efforts to view the world from the perspective of their patients’ or clients’ suffering mean that they tend to suffer. According to Figley (2002), the meaning of compassion is to bear suffering. Those who are involved in a care profession are susceptible to experiencing compassion fatigue. Compassion
fatigue, like any other kind of fatigue, reduces their capacity or even their interest to bear the suffering of others.

The subjective burden of caregiving is difficult to comprehend and to measure through quantitative studies. Subjective burden focuses on the emotional and psychological elements of caregiving stress. Subjective burden is analogous to pain; everyone has a different threshold and it is contingent on factors confounded by the objective burden. Subjective burden may increase due to a lack of sleep, illness, somatic manifestations, and/or depression, which may have been a consequence of caregiving but now magnifies the caregiving obligation.

In a hospice setting, the person who assumes the role of caregiving and nurturing for the chronically ill is the number one target for the accumulation of stress and the development of physical, mental, and emotional symptoms, resulting in compassion fatigue and burnout. Providing care for a chronically ill loved one has many rewards; it facilitates involvement and brings closeness between the caregiver and the care recipient. The experiences may have detrimental effects on the immediate care provider’s quality of life (Goldman, 2002). Previous studies have found a correlation between providing care for the chronically ill family member and the development of psychological symptoms, as well as the negative effect on the caregiver’s social and family life.

Compassion fatigue, in its simplest form, has been described as the stress, strain and weariness of caring for others who are suffering from a medical or psychological problem (Thomas & Wilson, 2004), being either those who aid in a professional capacity or family and friends of those in pain and suffering.
2.3 AETIOLOGY OF COMPASSION FATIGUE

Empathy and emotional energy are the driving forces in effectively working with those in pain and suffering in general, establishing and maintaining an effective caregiver and patient alliance, and the delivering of effective service and care that is coupled with an empathic response (Figley, 1995, 2002).

Compassion fatigue is the caregiver’s empathic ability to be aware of other people’s pain and suffering. Therefore, empathy is the driving force behind compassion stress. Figley (2002) asserts that the ability to empathize is a cornerstone for helping others and being vulnerable to the cost of caring. The more one is exposed to others’ pain and suffering, the more empathetic he or she tends to be, increasing the prevalence of compassion stress and tension that may result in one being preoccupied with others’ pain and suffering.

Empathic concern is what motivates individuals to respond to people in need. High motivation to help others, complemented by empathy and appropriate training and knowledge, is what will ensure that the individuals are not negatively affected by others’ pain and suffering (Figley, 2002). Empathy and motivation alone are not enough to ensure that individuals are able to cope effectively with the effect of witnessing and the direct exposure to others’ pain and suffering.

2.4 DEFINING PALLIATIVE CARE

WHO (2010) defines palliative care as an approach that aims at improving the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering. Palliative care was developed in
response to the needs of patients with advanced cancer, neurological illness, cardiac failure, dementia, and HIV/Aids. Worldwide, around 56 million people die each year from the abovementioned diseases, more than a million every week. Around 80 percent of these deaths are in developing countries (Clark & Wright, 2002). According to the annual statistics by the HPCA (HPCA, 2011), there are 94,585 patients for whom they care in South Africa. This number increased significantly from 47,904 in 2008. The majority of these patients were unable to contribute to the cost of care, putting a strain on the health system in South Africa. In 2011 an estimated amount of R24 million was allocated to the health system budget.

These statistics include patients diagnosed with cancer, HIV/Aids and chronic illnesses that persist over time, like asthma, chronic heart disease, strokes, chronic bronchitis, diabetes and mental illnesses. With chronic illnesses, a more complex and professional care is required to meet the patient’s physical and psychological care in accomplishing treatment goals. The WHO health system approach is a holistic way of providing healthcare services by integrating early identification, impeccable assessment and treatment, pain management, physical, psychosocial and spiritual care for patients from diagnostic to their end of life.

Originally, palliative care was linked to situations in which patients were clearly near the end of life. However, the use of new, aggressive cancer treatments has forced us to re-conceptualise palliative care as services integrated throughout the patient’s and family’s illness experience. There is obviously a need for attention and allocation of resources to the palliative care services in the country, and these resources are mostly non-governmental organisations (NGOs) or privately owned.
Palliative care has continued to evolve beyond end-of-life care to encompass all aspects of the disease continuum, from illness to bereavement, to patients and families realizing their full potential to live even when they are dying. Palliative caregivers are trained to help patients overcome the most challenging times during their periods of illness. Their role of caring does not only end with their patients but they also play a major role in ensuring that the patients’ family is consoled and gets the support necessary to cope well with their family member’s or loved one’s experiences of trauma.

When palliative caregivers are unable to cope and deal well with their patients’ pain and suffering, they may experience some level of impairment where they may display unhealthy empathy, personality problems, poor coping skills, poor interpersonal skills, or other behavioural problems. There is an overlap in the literature between caregivers’ wellness and literature on compassion fatigue, burnout, secondary trauma, and the caregivers’ ability to cope and withstand their patients’ pain and suffering.

2.5 COMPASSION FATIGUE AND RELATED CONCEPTS

Compassion Fatigue, Burnout, Vicarious Traumatization and Secondary Traumatic Stress

According to Figley (1995), the interaction of caregiver and patient can result in unconscious forces that are powerful enough to result in the caregiver being unable to maintain a healthy balance of empathy and objectivity. It has been documented that individuals who display high levels of empathy and empathic response to a patient’s pain, suffering, or traumatic experience, are more vulnerable to experiencing compassion stress.
Coetzee and Klopper (2010) refer to compassion fatigue as a state where compassionate energy that is expended by caregivers has surpassed their restorative process, with recovery power being lost. Their study analysed the concept of compassion fatigue within the nursing practice and they found that there is evidence of the compassion discomfort and compassion stress within the nurses who are suffering from compassion fatigue. It found that indicative signs of compassion fatigue are the physical effects (burnout, lack of energy, wearying, loss of strength, lack of sleep), emotional effects (being emotionally overwhelmed, irritability, desensitization), social effects (indifference, unresponsiveness) and spiritual effects (lack of spiritual awareness).

The helping professionals may experience recurrent and intrusive distressing recollections of the traumatic event as it is experienced and witnessed through the relationship with their patients, including thoughts, perceptions, images and possible recurrent distressing dreams of the event (Figley, 1995). It is not only personal experiences with trauma that can result in individuals experiencing compassion fatigue, but those who help others in time of strife or traumatic events are also at risk.

There have been more texts and research that explored the phenomenon of traumatization of helpers through their efforts of helping (Figley, 1995; Pearlman & Saakvitne, 1995; Stamm, 2010). The terms that have been coined as the cornerstone of the vocabulary that describes the negative effects that helpers suffer when working with traumatized patients and clients are “vicarious traumatization” (McCann & Pearlman, 1990; Pearlman &
“secondary traumatic stress” (Figley, 1995; Stamm, 2010), and “compassion fatigue” (Figley, 1995). Studies that have explored compassion fatigue, vicarious trauma, and secondary traumatic stress often emphasise the significant and enduring repercussions that individuals deal with when they experience some level of discomfort when they encounter any kind of trauma. Individuals tend to process experiences and events in a variety of different ways, thus an event that may be experienced by one individual as traumatic may not be experienced by the other individual as traumatic (Herman, 1997). Not every individual would therefore experience negative effects when working with traumatized patients.

Joinson (1992) reports that the field of caregiving has been prone to the development of compassion fatigue or vicarious trauma. Therefore, it is strongly advisable that professionals be aware of the symptoms of compassion fatigue as they bear emotionally overwhelming and life-changing events. Also, Joinson (1992) has related that compassion fatigue is very hard to identify or recognise unless one is aware of the symptoms. It is vital that the profession of caregiving becomes familiar with the signs, symptoms, and treatment of compassion fatigue.

The physical and the emotional impacts of caring within the often stress-filled healthcare environment are gaining increasing attention, not only in the healthcare environment but also within the psychology and the research field. Compassion fatigue has primarily been studied within the field of psychotherapy and emergency medicine (Yang & Kim, 2012).

According to Figley (2002), compassion fatigue is a negative aspect of the helping professionals within the health professions which results in burnout. Doman (2010) defines
burnout as an experience of physical, emotional, and mental exhaustion, caused by long-term involvement in situations that are emotionally demanding. Burnout and compassion fatigue are very similar, as they both affect the professional’s ability to render effective services as well as maintaining effective professional and personal relationships negatively (Collins & Long, 2003; Figley, 1995, 2002, 2006). Burnout presents itself in a more gradual process of wearing down of caregivers who feel overwhelmed by their work and their perceived inability to create positive change for their patients (Doman, 2010). Compassion fatigue, on the other hand, is more sudden and acute and results from overwork that can negatively impact an individual’s work in any profession (Collins & Long, 2003).

Compassion fatigue is not merely a response to trauma exposure, but rather it entails exposure to trauma while one is involved primarily with traumatized patients (Elkonin & Van der Vyver, 2011). Burnout is defined in terms of three components: emotional exhaustion, depersonalization, and reduced personal accomplishment (Doman, 2010).

The level of compassion fatigue was found to vary according to nursing specialties in the following studies: “Positive and negative emotional responses to work-related trauma of intensive care nurses in private healthcare facilities” (Elkonin & Van der Vyver, 2011). The stressors experienced by caregivers contribute to the development of secondary and vicarious trauma and, if untreated, burnout (Elkonin & Van der Vyver, 2011). Secondary traumatic stress has been defined as a destructive emotional distress that results from individuals’ encounter with a traumatized and suffering patient, being either physical or emotional (Nimmo & Huggard, 2013).
In a study done on 75 intensive care nurses, Elkonin and Van der Vyver (2011) explored work-related positive and negative emotions (compassion satisfaction, compassion fatigue, burnout and silencing response) experienced by intensive care nurses working in the private healthcare facility. The majority of the participants (n=22) reported a moderate to high potential for experiencing compassion satisfaction. These findings indicate that the majority of intensive care nurses who participated in this study experience pleasure in their work and are better able to meet the demands of their work, and to deal more effectively with stress and anxiety. The experience of compassion satisfaction means that the nurses have a greater sense of wellness, which will enhance their personal growth (Bowles, 2009). Personal growth and a positive outlook in one’s work or experiences lead to positive emotional, cognitive and physical wellbeing.

Doman (2010) looked at whether greater compassion fatigue and greater burnout would be associated with less overall subjective happiness for mental healthcare providers. The study indicated that mental healthcare providers experiencing a greater degree of compassion fatigue and burnout are less likely to experience subjective happiness. Subjective happiness evolves from positive psychology, where individuals have the capacity to be happy and meet patients’ needs regardless of adverse circumstances (Coetzee & Klopper, 2010). It is clear that there are individuals who are resilient to the exposure to traumatic events. This is supported by Stamm’s (1998) view that not all trauma workers succumb to secondary traumatic stress, and she believes that some individuals may have a protective mechanism that helps them to maintain their wellbeing.

Studying mental healthcare providers, Doman (2010) predicted that mental healthcare workers will report a greater degree of CF, greater burnout and less compassion
satisfaction. Contrary to previous findings (Collins & Long, 2003; Figley, 1995, 2002; Pearlman & Saakvitne, 1995; Sabo, 2008), there was no statistical evidence to support Doman’s (2010) predictions. A possible explanation for the results of the finding that participants are resilient is the role of general self-care. The researcher believes that getting enough rest, eating a well-balanced diet, exercising, utilising the available support system as well as the fact that the population was graduate students who still received additional resources and guidance, played a role. After all, compassion fatigue develops gradually and the participants have not yet felt the overwhelming impact of working with patients experiencing trauma and their perceived inability to make a positive change (Collins & Long, 2003; Figley, 2006; Stamm, 2010).

Looking at the triggers of compassion fatigue, where excessive empathy and compassion for patients result in compassion fatigue, Yoder (2008) found that stress and life demands can trigger compassion fatigue and burnout among nurses who care for patients who are experiencing serious physical and/or emotional threats or even imminent death.

The energy and inspiration of caregivers to connect and share in their patients’ suffering is the driving force behind compassion satisfaction. It is therefore the personal reward and fulfilment of the caregivers to witness their patients being alleviated and relieved of their pain and suffering. The experiences of novice counsellors are that they not only experienced the negative psychological effects, but they also experienced positive effects and feelings of lightness (Figley, 2006). The positive effects were due to the novice counsellors witnessing the difference and change they made to the patients’ lives.
Giles (2011) studied the prevalence of compassion fatigue in registered nurses employed by the home-care nursing industry in South Africa. Giles (2011) used Professional Quality of Life (ProQOL) Version 5 as an instrument to analyse data. ProQOL is an instrument that is more psychometrically sound to measure compassion fatigue/secondary traumatic stress, burnout and compassion satisfaction (Stamm, 2010). The survey was conducted among 60 registered nurses (RNs) with a response rate of 58%. The average score for burnout was found to be 22.9% and secondary traumatic stress 20.9%, with compassion satisfaction scoring 41.3%. The study’s findings indicate that there is a low risk of compassion fatigue among registered nurses employed by the home-care nursing industry in South Africa. It was found that the nurses in this study derive more pleasure from being able to help and do well for someone else. The level of satisfaction that they derive from helping others is used as a constructive energy resource that strengthens the lines of defence to offset the progression of compassion fatigue.

Support from friends and family has been identified as the most essential component to ensure job satisfaction (Giles, 2011). Psychologists use the term “caregiver burden” to describe the physical, emotional, financial and social problems associated with caregiving (Sabo, 2011). Literature on caregiver burden distinguishes two ways that burden can be assessed. Objective burden assesses the extent to which caregiving disrupts daily routines and social relationships and negatively affects resources (Sabo, 2011). This is characterized by loss of income, family friction, reduced social contacts and reduced energy.

Subjective burden, on the other hand, assesses the caregivers’ perceptions of and reactions to caregiving demands, where they report “feeling trapped”, “feeling nervous”, depressed
about their relationship with the care recipients, or “resenting caregiving tasks” (Sabo, 2011). Expectations by caregivers that providing a specific level of care will lead to positive outcomes for every patient may setup caregivers to experience high stress level when their expectations are not met (Sabo, 2011). It is therefore unrealistic expectations that may lead to caregivers experiencing increased burden, emotional exhaustion and ultimately compassion fatigue.

Compassion fatigue presents itself in the same way as PTSD in the sense that the symptomology is the same. Compassion fatigue is the reaction of experiencing STSD, where the natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other can result in a caregiver experiencing a significant level of tension and preoccupation with the patient’s trauma (Figley, 1995). It is therefore the exposure to suffering in another person which leads to compassion fatigue (Sabo, 2008). It is what Figley (1995) calls the function of bearing witness to the suffering of others. Studies showed that PTSD is present when an individual experiences a high level of stress that continues after the threat of death or harm had passed, and this results in persistent distress that continues to progress and interferes with the individual’s life (Etherington, 2003).

STSD is a syndrome with symptoms almost identical to PTSD, except that with STSD symptoms are triggered by the exposure to knowledge about the traumatizing event experienced by the significant other, and in PTSD symptoms are directly connected to the sufferer or the person who directly experiences the harm (Figley, 1995). The concept of secondary traumatic stress (STS) was used to identify stress reactions that occurred in caseworkers who provided care to traumatized children and other individuals who
developed stress reactions due to a secondary exposure to trauma (Figley, 1995). Figley (2002) later coined the term compassion fatigue as a more user-friendly name for STS, and he referred to the concept as “the burden of attending to suffering” (Figley, 2002, p.1).

Compassion fatigue can result in professionals having a high risk of making poor professional decisions and being personally and professionally withdrawn (Collins & Long, 2003; Stamm, 1998). It is therefore a lack of positive emotional response of the caregiver professionals towards their patients’ pain and suffering, creating a lack of coping with stressful situations. As such, caregiver professionals may experience long-term negative effects on their abilities to perform their professional duties and even in their social lives. It is expected that they will be unable to maintain a safe and effective patient-caregiver relationship.

2.6 GENERAL RESEARCH FINDINGS

Professionals caring for patients in a standard patient care environment involve multiple dynamics that may impact on the individual over time. The dynamics, as reported by Sudeck (2012), are short-staff situations, busy on-call schedules, a lack of support, heavy patient caseloads, patients’ pain and suffering, time management challenges, patients lost, and displayed anger from patients and family members. According to these dynamics, when an individual is confronted with a stress or feeling of helplessness due to a high level of exposure to trauma, pain and suffering, the context of relationships with their primary partners, family members, extended family, friends, religious and cultural communities and even colleagues create a different outlook and perspective that can drastically shift their sense of self and meaning towards them witnessing their patients’ pain and suffering. Not only does feeling helpless result from the professional caregivers’ personal relationships,
but also from the relationships between them, their work experiences and their patients’ relationships (Palomino, 2008). Helplessness results from caregivers’ experience of being out of control or being unable to do something about their patients’ pain and suffering (Palomino, 2008).

It was reported by Yang and Kim (2012) that literature on compassion fatigue first appeared in the early ‘90s. They further reported that the first study to investigate compassion fatigue in nurses was published in 2000. Furthermore, there were very few research papers per year prior to 2005. However, from 2006 to 2011, more papers were published on compassion fatigue, reporting a total of 31 papers, with eight papers reporting on compassion fatigue within the healthcare and caregiving profession.

According to Figley (2006), nurses are more at risk and vulnerable to compassion fatigue, because they are constantly exposed to patients’ trauma and they are more compassionate. Although research on nurses’ experiences and the prevalence of compassion fatigue was done (Braunschneider, 2013; Giles, 2011; Petleski, 2013; Yoder, 2008), there was also research done on the phenomenon of compassion fatigue in counsellors (Bowles, 2009; Browning, 2014), social workers (Lawson, 2008), foster parents (Parker, 2009), mental healthcare workers (Collins & Long, 2003; Doman, 2010; Hasson, 2013), as well as palliative caregivers and hospice caregivers (Sudeck, 2012; Uren, 2009), all focusing on the notion of the impact, understanding and nature of negative physical, emotional, social, spiritual, and the cognitive toll experienced by the helping professionals.

The main component of this literature review is the description of professional helpers’ vulnerability to the exposure of their clients’ or patients’ pain and suffering, which may
possibly lead to the experiences of stress, fatigue, feelings of helplessness and even emotional exhaustion (Figley, 2002). Vulnerability to work-related stress results from factors such as the helping professional’s relationship, level of empathy and engagement, contributing to the helping professional’s vulnerability to work-related stress (Sabo, 2011).

Abendroth and Flannery (2006), Coetzee and Klopper (2010), and Palomino (2008), refer to compassion fatigue as a state where compassionate energy that is expended by caregivers has surpassed their restorative process, with recovery power being lost. The study analysed the concept of compassion fatigue within the nursing practice and it was found that there is evidence of compassion discomfort and compassion stress within the nurses who are suffering from compassion fatigue. In an attempt to measure compassion fatigue among nurses who were employed in home care, the emergency department of a hospital, intensive care units, progressive care units, oncology units and medical-surgical units, Yoder (2008) found trigger situations that elicited symptoms of compassion fatigue across all the work settings stated above, including caring for patients who died, patients with more severe medical conditions, patients’ challenging behaviour, workload, and personal issues.

The helping professionals may experience recurrent and intrusive distressing recollections of the traumatic event as it is experienced and witnessed through the relationship with their patients, including thoughts, perceptions, images and possible recurrent distressing dreams of the event (Figley, 1995). It is not only personal experiences with trauma that can result in individuals experiencing compassion fatigue, but those who help others in time of strife or traumatic events are also at risk. The stressors experienced by caregivers contribute to
the development of secondary and vicarious trauma and, if untreated, burnout (Elkonin & Van der Vyver, 2011).

Looking at the prevalence of burnout and compassion fatigue in occupational nurses and therapists, Day and Anderson (2011) found that both occupational nurses and therapists tend to experience feelings of hopelessness, helplessness, emotional disengagement, and guilt, thus indicating the negative experiences of both types of professionals (Day & Anderson, 2011; Sherman, 2004). With research focusing more on occupational nurses, Sherman (2004) found that exposure to death and bereavement can increase the nurses’ awareness of their own losses and vulnerabilities, this being due to the unrealistic high expectations they place on themselves with regard to ensuring the healing and wellbeing of their patients. Day and Anderson (2011) found that as patients’ health deteriorates, occupational nurses go through grief, guilt and resentment resulting from compassion fatigue.

There seems to be a pattern of self-blame and a feeling of responsibility when they lose a patient or even when the patient is in inconsolable pain. These are some of the factors that cause caregivers to become even more vulnerable to compassion fatigue. Schaufeli and Enzmann (1998) maintain that the working conditions of the healthcare professionals are in particular contributing factors to the vulnerability to occupational stress.

2.6.1 Compassion fatigue effects on palliative caregivers’ emotional functioning

There is a growing body of literature that suggests that oncology nurses are at risk of compassion fatigue (Ferrans, 1990; Pasacreta & McCorkle, 2001; Potter et al., 2010). Pasacreta and McCorkle (2001) explored the impact of interventions on cancer caregivers
for the Annual Review of Nursing Research. Their findings confirmed the chronic and consuming nature of cancer caregiving. Potter et al. (2010) found it essential to analyse the prevalence of burnout and compassion fatigue among oncology healthcare providers. Pasacreta and McCorkle (2001) support Ferrans’ (1990) findings that caring for patients with cancer generates significant work-related stress that can result in employee mental exhaustion.

Peterson, Demerouti, Bergström, Samuelsson, Åsberg and Nygren (2008) investigated how burnout relates to self-reported physical and mental health, sleep disturbance, memory and lifestyle factors in Swedish healthcare workers. It was found that burnout is associated with poorer self-rated health, more depression and anxiety, more sleep disturbance and perceived impaired memory. Exhaustion, among other factors, therefore appears to be the most obvious manifestation of burnout, which also correlates positively with workload and other stress-related outcomes, such as compassion fatigue that puts healthcare professionals at high risk of poor professional judgment. As previously mentioned, this may gradually or suddenly lead to work-related stress and emotional exhaustion.

Jisika (1995) asserts that the loss of patients by nurses may be equated with personal failure and loss of self-esteem, and this may result in distressing experiences for them (Tyler & Ellison, 1994). Furthermore, Elkonin and Van der Vyver (2011) in their quantitative study, aimed to explore and describe the presence of compassion satisfaction and compassion fatigue in intensive care nurses. The sample consisted of 30 registered nurses and they found that 73% (n=22) of the respondents reported a moderate to high potential for experiencing compassion satisfaction. A slight negative correlation (r=-0.19) was found between compassion satisfaction and compassion fatigue. These findings may
be due to the nurses’ ability to deal positively with their daily work experiences, finding meaning in their work and having satisfaction in knowing that they were able to help their patients (Browning, 2014).

2.6.2 Compassion fatigue effects on palliative caregivers’ physiological functioning

Nimmo and Huggard (2013) attempted to explore the existence of compassion fatigue among physicians, but they found no literature and articles available on the description of some of the trauma constructs mentioned earlier, which are vicarious trauma and secondary traumatic stress. There are two studies that researched the presence of compassion fatigue in physicians (Reese, 2008) and vicarious trauma (Way, VanDeusen,& Cottrell, 2007). Both studies identified physicians’ age as a construct that is related to compassion fatigue or vicarious trauma.

Reese (2008) reported that it is not only age that has a significant relationship to compassion fatigue, but also spirituality. It is not only one factor that may be associated with compassion fatigue, but rather multiple factors. Some of the factors that were identified by Figley (2002) are personal factors, professional factors, psychological factors, support factors and coping factors. Ongoing exposure to these factors may lead caregivers to experiencing compassion fatigue as another form of occupational stress. In a narrative study to explore the lived experiences of vicarious trauma in care providers, it was found that the participants experienced acute and chronic illnesses as a result of experiencing vicarious trauma (Melius, 2013). Similar to compassion fatigue, vicarious trauma is a secondary traumatic stress that individuals experience when they go through any level of work-related discomfort and any kind of work-related trauma. It was found that the
participants had shared experiences of chronic exhaustion, chronic headaches and sleep deprivation that had a significant impact on both their work and personal lives.

Sabo (2011) reported that some of the factors that may increase compassion fatigue among caregiver professionals are a poor collaborative work environment, a lack of social support, negative work experience, training and work-orientation factors, heavy workloads, increased time in contact with patients, and long work hours. One or a combination of the factors mentioned above may lead to stress or emotions that are associated with compassion fatigue, as either a causative or consequent factor. These are factors that are similar to Figley’s (2002) findings and they are associated with caregivers feeling overwhelmed by their patients’ distressing experiences, leading to caregivers becoming overly empathetic. Contrary to Figley’s (2002) findings, Coetzee and Klopper (2010) indicated that unresponsiveness to patients’ pain, and callousness and indifference towards patients’ pain and suffering are some of indicative signs of compassion fatigue. The caregivers get to a point where their compassionate care abilities are altered and they are unable to respond with compassion to others’ pain and suffering.

Any professional caregiver is vulnerable to compassion fatigue. Symptoms can be as minimal as losing something, forgetting names and words, or having a shortened attention span (Figley, 2002). More troubling symptoms are exhaustion, headaches, or stomach aches. Resistance to illnesses is low and sickness occurs more frequently when one is suffering from compassion fatigue (Figley, 2002; Sabo, 2011). Depression can occur, as well as frequent anger outbursts (Joinson, 1992). A high level of stress is associated with a number of physiological illnesses, such as low energy, headaches, nausea, upset stomach, heart problems, frequent colds and infections, nervousness, and insomnia. These are
physical symptoms that will lead to increased absenteeism and a loss of energy or interest to perform their daily work responsibilities of caring for their patients.

2.6.3 Compassion fatigue effects on palliative caregivers’ social functioning

With research by Pearlman and Saakvitne (1995) in the helping professionals or caregivers, compassion is a driving force for the basic desire to help others. Therefore compassion can be seen as being at the continuum between fatigue and satisfaction. It is evident that not only the witnessing of patients’ trauma and suffering, but also experiencing patient loss, can contribute to caregivers experiencing compassion fatigue. Pearlman and Saakvitne (1995) found that repeated exposure to clients’ or patients’ trauma puts professionals at more risk of experiencing negative effects as a result of their patients’ trauma.

Parker (2009) sought to better understand the relationship between compassion fatigue and foster parenting. It was found that there is a higher risk of compassion fatigue in foster parents than in the caregivers lives, due to the foster parents not receiving adequate training on dealing and coping with stress as caregivers do.

In support of Parker’s (2009) findings, a previous study by Farmer, Lipscombe and Moyers (2005) found that foster parents experienced less stress and strain when they had support from friends and local professionals. Social and family support therefore plays a positive role in alleviating the risk of compassion fatigue.

The interpersonal relations between the patient, family systems, social system and the caregiver are important to better understand how compassion fatigue affects or is
experienced by the caregiver professional (Edwards & Karnilowicz, 2013). The dynamics of trauma and work stress are often re-enacted in these systems. It is therefore important to understand palliative caregivers’ experiences of compassion fatigue with consideration to their interpersonal relations with these systems.

A supportive relationship from family has a significant impact on the caregiver professionals’ ability to counteract compassion fatigue and to have a positive outlook in their work (Browning, 2014). In an attempt to investigate and comprehend the lived experiences of traumatic brain injury (TBI) counsellors’ experiences with community reintegration, Browning (2014) interviewed ten counsellors and found that family and social support has the biggest impact on the counsellors’ quality of life. Therefore a lack of support from family may lead to feelings of helplessness, which will lead to social isolation and emotional problems.

Exploring how professionals in helping professions describe their experiences with support, services and assistance that are available to them, Peters (2010) found that some of the participants reported that they receive little support and assistance in their place of work. However, the participants reported family members and peers as their main sources of support. Other participants did not specifically name support and assistance as a helping strategy, but rather they described how they lack effective support and assistance (Peters, 2010). What stood out for them and what they felt needed to be revealed was the lack of support and assistance that they had hoped they should or could receive to assist them in coping with their daily challenges.
A holistic approach to palliative care has focused solely on patient care, neglecting that it is important to acknowledge the valuable role that is played by caregivers and not realizing that compassion fatigue impacts their lives holistically (Chauhan & Naidoo, 2006). Bishop and Scudder (1999) found that compassion fatigue has an impact on both the personal and professional domain of functioning, and they suggested that if compassion fatigue was looked at holistically, it would enable the context for exploring more meaningful caregiving practice. Consistent with Chauhan and Naidoo’s (2006) findings, there is a need for a more holistic exploratory approach to understanding the rewards and challenges from the perspective of the professional caregivers (Edwards & Karnilowicz, 2013).

There are studies that focused on work environment, structure and organisational culture in influencing employee health (Golaszewski, Allen, & Edington, 2008). The primary themes for ecological thinking are interdependence and mutual interaction among person and organism, as well as studying behaviour in a natural setting (Golaszewski et al., 2008). It was also found that context is more important in a broader sense as there is a need to consider the effect of compassion fatigue on palliative caregivers and how they experience it in an organisational context; it is important to understand behaviour in context and the context needs to be understood in terms of how different individuals experience a particular phenomenon in that context (Golaszewski et al., 2008).

2.6.4 Compassion fatigue and spirituality

A study conducted by Clark, Leedy, McDonald, Muller, Lamb and Mendez (2007) aimed at determining the prevalence of spirituality among a team of employees at a hospice. They questioned whether there was a relationship between spirituality and direct causal effect on job satisfaction. They also investigated whether there was a structural relationship between
spirituality, integration of spirituality at work, level of self-actualisation, and employee job satisfaction (Clark et al., 2007).

Clark et al. (2007) studied 270 hospice and palliative care employees in Florida in the United States. With 215 (79%) responses, there was a moderate to small indication that those employees who have strong spiritual beliefs are more likely to incorporate their beliefs at work (r=0.34); this enabled them to be more self-actualised (r=0.50), and they have the highest rate of job satisfaction (r=0.28). A high level of spirituality rated at 98% among the respondents is included, and this could be due to them addressing the issues of pain, suffering, and all other aspects that are associated or related to the end of life. Spirituality is therefore part of the holistic perspective of palliative care and all other caring professions in general.

According to Gentry (2012), spirituality is a humans’ ability to find comfort, support, and meaning from a power greater than themselves, therefore it may be a source of optimism because it offers a sense of hope and wellbeing, heightened compassion satisfaction and lowered compassion fatigue and burnout. Clark et al. (2007) stated that hospice workers are more spiritual compared to other workers. They stated that, instead of being negatively impacted by continuously being exposed to their patients’ pain, suffering and trauma, they appear to experience an increased compassion satisfaction in several areas of their lives.

Myers and Williard (2003) recommended that training and support that promote human spirituality as the core element of individuals are useful to prepare caregiving professionals for the challenges that may affect their caregiving responsibilities negatively. Spirituality plays an essential role in ensuring that individuals are capable of understanding their
personal abilities and also to be aware of any physiological changes. Spirituality therefore enables humans to be in touch with their inner wellbeing or their emotional health.

Contrary to Myers and Williard (2003) and Clark et al. (2007), Reese (2008) examined the relationship between the constructs burnout, compassion fatigue and compassion satisfaction and found that there is a statistical relationship between spirituality and compassion fatigue. Spirituality is one of the issues that is reported to be influenced by compassion fatigue (Robinson, 2005). Robinson (2005) asserts that it is rather important to question whether vicarious trauma and compassion fatigue may alter caregivers’ worldview and spirituality. Coetzee and Klopper (2010) reported that the spiritual effects of poor judgment, the disinterest in introspection and the intellectual effect of disorderliness indicate signs of compassion fatigue.

2.6.5 **Interventions and support**

Compassion fatigue can become debilitating for those professionals who find their jobs not to be what they have expected them to be or if there is a lack of support, not only within their professional setting, but in their social setting as well. Palliative caregivers tend to not only attend to their patients, but they also professionally open their hearts and genuinely care for their patients completely in all aspects. Over-caring and excessive empathy of caregiving professionals for their patients make them more vulnerable and likely to suffer from compassion fatigue (Lawson, 2008).

In a quantitative study, Abendroth and Flannery (2006) looked at the prevalence of the risk of compassion fatigue with the focus on demographic and work-related factors. The study was conducted among hospice nurses employed in hospice organisations from various
districts in the state of Florida (USA). A total of 583 surveys were distributed to all the various districts and at a Hospice Symposium, with a 38.3% (n = 166) response rate from mailed surveys and 33% (n = 50) from the symposium survey. The findings indicate that there is an association between compassion fatigue and work variables, and it was found that caregivers possess defence mechanisms which enable them to cope when caring for terminally ill patients (Abendroth & Flannery, 2006). The study revealed that nearly 80% (n = 170) of the sampled hospice nurses are at a moderate to high risk of compassion fatigue, and 17% (n = 37) of the nurses indicated that they did not receive any form of support after a patient’s traumatic death.

Those who cope well with the exposure to terminally ill patients’ pain and suffering scored low in compassion fatigue and those who could not cope due to a lack of defense mechanisms scored high in compassion fatigue (Abendroth & Flannery, 2006). This is an indication of the prevalence of compassion fatigue in palliative caregivers who lacked defense mechanisms that enable them to cope well with their daily encounters with terminally ill patients. Looking at the predicting risk factors of compassion fatigue, Abendroth and Flannery (2006) found that there was a correlation between the risk factors and compassion fatigue irrespective of whether caregivers experienced or were exposed to patients’ trauma or not (Abendroth & Flannery, 2006).

The key risk factors identified by Abendroth and Flannery (2006) were stress, trauma, anxiety, life demands, and excessive empathy. It is evident that not only one variable can contribute to the development of compassion fatigue, but rather there could be a combination of variables. Predicting the risk factors of compassion fatigue is beneficial in contributing to the health and wellbeing of palliative caregivers through the development
of ongoing support and preventative measures that can be implemented, with the focus on the identified risk factors to reduce the prevalence of compassion fatigue.

Abendroth and Flannery (2006) found that demographic and work-related factors were of little discriminating value for describing the prevalence of risk for compassion fatigue, implying that there are nurses who possess defense mechanisms that enable them to cope with caring for the terminally ill patients. There was also a positive response to the tendency to self-sacrifice by the nurses who scored high in the risk of compassion fatigue category. These nurses cared more for their patients’ needs than for their own needs, thus reflecting an unhealthy level of empathy. An unhealthy level of empathy, coupled with consistent prolonged exposure to traumatized and terminally ill patients, is regarded as a risk factor for compassion fatigue (Sabo, 2011).

There has always been an expectation from our society that caregivers should be more compassionate without showing distress, as it is suggested by literature that caregivers are expected to keep their distress in the closet even though patient care affects them emotionally, intellectually as well as professionally. Doka, Rushton and Thorstenson (1994), and Sabo (2008), suggest that a shift from the pathology of compassion fatigue to predictive factors is needed to allow the caregivers enough support and adequate resources that will enable the caregivers to cope with compassion fatigue.

The danger of experiencing compassion fatigue does not necessarily result from caregivers sharing the space with patients or even a close and constant interaction, but rather from the lack of professional-patient engagement that is not supported (Austin, Goble, Leier, & Byrne, 2009). Austin et al. (2009) suggest that developing a greater understanding of
compassion fatigue will contribute to an understanding of the kind of support that is essential in fostering quality work. Therefore the framework of social support is crucial to channel resources such as education, awareness, understanding, knowledge and creating dialogue for compassion fatigue.

The physical, emotional, spiritual and intellectual demands on caregiver professionals are far greater as patients are chronically ill and their illness advances, exposing caregivers to secondary stress and therefore more likely to develop compassion fatigue in their workplace (Petleski, 2013). Orenstein (2003) maintains that the health and wellbeing of the caregivers had to be considered when designing healthcare training and palliative caregivers’ intervention programmes.

There is further literature that indicates that advanced training, employee support assistance and education programmes for palliative caregivers could counteract the threat of compassion fatigue (Elkonin & Van der Vyver, 2011; Orenstein, 2003; Petleski, 2013). Furthermore employees should create an organisational culture that will acknowledge and normalise secondary trauma reactions and offer practical support for their staff (Elkonin & Van der Vyver, 2011; Orenstein, 2003; Petleski, 2013). Although training and support are crucial for palliative caregivers, there is always neglect of the palliative caregivers’ experiences and the meaning they ascribe to their experiences of compassion fatigue. This is a crucial insight in the development and design of palliative care training and interventions programmes.

According to Petleski (2013) and Hasson (2013), educational programmes, support groups, employee assistance and counselling services enabled caregivers to develop coping skills,
stress management and reduced their risks of work-related compassion fatigue. These are support mechanisms that may be put in place in order to assist palliative caregivers in coping more effectively with their working conditions and combating the development of compassion fatigue.

Programmes and interventions that Petleski (2013) identified have been reported to be more effective in assisting caregiver professionals to cope with compassion fatigue. In addition to the above support mechanisms to enable caregivers to cope well with the constant exposure to trauma, supervision was also reported to be one of the most common and effective ways of increasing confidence and contributed to their positive experiences as therapists.

Research suggests that strategies to support caregivers would reduce caregivers’ burden, potentially preventing psychosocial distress; this is a proactive measure where the palliative caregiver will be provided with the necessary support to cope well with the underlying distress that may result from their work (Orenstein, 2003). As Pearlman and Saakvitne (1995) related, the importance of support within the caregiving environment should not be restricted to training programmes in order to alert changes in caregivers’ behaviour and reactions to patients, as this will allow immediate interventions in curbing the problem of compassion fatigue. Within the caregiving profession it is imperative that the culture of sharing experiences and reflecting on their experiences is nurtured. Not only will this maintain a strong professional philosophy, but it will also help in the caregivers’ restructuring of their cognitive framework regarding their experiences.
Developing positive self-care strategies and healthy rituals are very important for caregivers to recover from and deal with compassion fatigue successfully. Interventions, prevention methods and treatments are powerful introspective and interactive models for caregivers to develop resiliency and coping skills to move towards a more intentional and less reactive professional and personal life. The successful resolution of compassion fatigue symptoms by professional caregivers is core to their resilience to any negative effects resulting from their exposure to their patients’ or clients’ trauma (Gentry & Baranowsky, 2013). Coetzee and Klopper (2010) reported that compassion fatigue needs to be effaced in its early stages of compassion discomfort and compassion stress to retain the power of recovery and full restoration of the previous level of compassionate functioning. The increase in risks, knowledge and understanding of the existence and indicators of compassion fatigue is essential to allow palliative care facilities to take adequate measures to prevent compassion fatigue, to be aware of those already experiencing compassion fatigue and to provide the necessary support interventions.

Through Gentry and Baranowsky’s (2013) search for interventions within the trauma care field, they developed the Accelerated Program for Compassion Fatigue (ARP). The ARP is a five-session model for the treatment of the deleterious effects helpers experience as a result of their caregiving work (Gentry & Baranowsky, 2013). The intervention is a training programme that focuses on the core training and rapid resiliency programme that enables caregiving professionals to journey successfully through their professions and gain the foundations for a long and healthy engagement in work/life and all the other social and interpersonal factors that are most likely to be negatively affected by compassion fatigue (Gentry & Baranowsky, 2013). There is a need for more support and resources for caregivers who go through stressful situations on a daily basis.
Due to the recurrent and intrusive nature of compassion fatigue, it is essential for the intervention programmes to be designed in such a way that they will be easily accessible to the caregivers at all times and that they will be able to address all the negative effects resulting from their experiences of compassion fatigue. Recognising the complexities of individuals working within the helping profession and understanding their professional journeys may just be the first step to gaining the foundation for a long and healthy engagement with their work and social life.

Stamm (1998) reported that positive skills and values modelled within intervention and support programmes serve as the basis for resilience that can aid caregivers in managing emotional reactions to working with traumatic and stressful life events or experiences of others. The concept of resilience helps in the understanding of why some professional caregivers might experience compassion fatigue or secondary trauma while others are capable of thriving throughout their profession (Stamm, 2010).

There is a need for effective ways to assist nurses and other healthcare workers in coping with work-related stress. Intervention may assist in the reduction of stress and all the elements of compassion fatigue and may even prevent burnout.

Looking at how pediatric oncology nurses deal with stressors and what effective strategies they use to deal with work-related stress, Zander and Hutton (2009) found that there were some 18 studies conducted; however, they were conducted in a variety of developed countries. Eight of the studies were conducted among oncology nurses and ten are related
to other general nursing fields. There was only one study that included allied health disciplines.

Zander and Hutton (2009) aimed to identify effective ways to assist nurses and other healthcare workers in coping with work-related stress, and interventions that would aid in stress reduction in the workplace. The research looked at how pediatric oncology nurses dealt with stressors and how managers and colleagues could enhance nurses’ coping strategies. A report from their analysis revealed that there are four themes that emerged:

1. Meaning;
2. Interventions;
3. Strategies; and
4. Commitment.

The theme ‘meaning’ refers to establishing meaning of work which impacts on professional relationships and boundaries.

Interventions include workshops to teach coping mechanisms for stress reduction and self-care.

Coping strategies are those behaviours which are feasible for nurses to use in dealing with work-related stress. There are two coping strategies that were listed by Figley (2002) that caregiving professionals use as a deterrence to compassion fatigue. A sense of achievement is the first strategy that he listed. Figley (2002) believes that when professionals experience a sense of achievement, they feel a sense of satisfaction, which lowers or prevents
compassion fatigue. A sense of achievement results from their ability or attempt to help their patients or clients. By feeling a sense of achievement, the caregiver is able to realise his or her role, limitations and responsibility as well as that of his or her patient or client (Figley, 2002).

The second strategy is that of disengagement. Disengagement is one of the coping mechanisms that enables the caregiver professionals to distance themselves from experiences, feelings, and thoughts that may be of a disturbing nature. By disengaging themselves, they are able to lower or even prevent their chances of experiencing compassion fatigue. Caregivers should establish boundaries; however, they still need to remain empathetic in order to decrease emotional distance between them and their patients or clients.

Figley (2002) assumes that empathy and emotional intensity are what drive caregiver professionals to work with those who are suffering. This is evident in caregiver professionals who have the skill to apply Figley’s coping strategies in their daily work environment and, when engaging with their patients, are capable of preventing and avoiding compassion fatigue. Stress management is critical for palliative caregivers to cope with distressing experiences positively.

Increasing training and continuous education within the professional caregivers’ work environment may prepare hospice caregivers to experience patients’ pain and suffering without being affected negatively by their experiences, and also serve as a preventative measure to maintain a healthy working environment (Clark et al., 2007; Trippany, White Kress, & Wilcoxon, 2004). Lawson (2008) indicated that understanding what type of
training and education opportunities are granted to hospice care workers would greatly increase knowledge for the helping professionals, therefore becoming less susceptible and at risk of experiencing compassion fatigue. Identifying the type of training and education that will be more effective and beneficial for professionals in the caregiving environment will increase the overall understanding of the coping skills that are required, support systems and the characteristics of caregivers who are at risk of going through compassion fatigue as well as of those who experience compassion satisfaction.

2.7 THEORETICAL FRAMEWORK

Environmental stressors are the central concepts of the physical and psychological wellbeing and health of individuals. A more holistic perspective is required to explore ways to address the environmental stressors that have a negative impact on the physical and psychological wellbeing of individuals (Miller, 2007). Compassion fatigue is a compilation of symptoms that is influenced by the impact of trauma work, such as exposure and empathy. Palliative caregiving service is more concerned with the pain management and reducing patients’ suffering than to live as comfortably as possible.

There are different views of compassion fatigue in the context of palliative care. When caregiving professionals are faced with a traumatic situation or exposed to patients’ distress, pain and suffering, they tend to restructure their own individual perceptions and realities in order to adapt or to cope (Trippany et al., 2004).

A few authors proposed the theoretical models to explain compassion fatigue, such as Beaton and Murphy’s (1995) theoretical systems model of secondary traumatic stress, Figley (1995) introduced the trauma transmission model, Dutton and Rubinstein (1995) the
ecological framework of trauma, and the constructivist self-development theory was introduced by McCann and Pearlman (1990). These models all share common characteristics of the factors which have an influence on the impact of trauma work, such as exposure, empathy and affect intensity (Harinarain, 2007).

The current research utilised the ecological theory as a theoretical basis in exploring palliative caregivers’ experiences of compassion fatigue within a hospice setting. This theory was used for the purpose of this study due to the relevance and applicability to palliative caregivers’ experiences of compassion fatigue within a hospice context. The ecological theory represents a more constructivist thinking, in that it is concerned with explicating the processes by which people come to describe, explain or otherwise account to the world in which they live, including themselves (Becvar & Becvar, 2006). Individuals’ perspectives and experiences of a phenomenon according to this theory are never the same, but rather unique to each individual.

Fitting within the chronic care context, the ecological theory highlights a combination of units, which are care activities, biological component, psychosocial, family unit and the healthcare organisation. The linkage of these units spreads across and beyond the healthcare environment to include the caregiver, the patient, family and social relations as connected to this link (Soubhi, 2007). It is not uncommon for caregivers’ experiences and their effects of caregiving to spread across and beyond the above combination of units. The theory views chronic care as a communal adaptive system to preserve, improve and expand patients’ lives to the maximum regardless of the constraints of their environment (Soubhi, 2007).
According to McCann and Pearlman (1990), the constructivist self-development theory is based on constructivism, the self, traumatic memories and adaptation to trauma. The theory was developed from a combination of concepts focused on three dimensions, namely psychodynamic, cognitive, and interpersonal conceptualisation. These concepts are the basic notion of explaining compassion fatigue based on the individuals’ sense of identity and understanding of the world around them (Trippany et al., 2004). Utilising ecological theory in this study can help to explain the multi-systemic impact of compassion fatigue on the wider organisational and social systems of palliative caregivers (Pack, 2013).

With regard to the theoretical systems model of secondary traumatic stress, the trauma experienced may be intensified by the trauma history of the caregiver (Beaton & Murphy, 1995; Salston & Figley, 2003), that results from indirect exposure to traumatic stress told by the patients. This model is based on the notion that people who are affected by other people’s pain and suffering may re-experience personal trauma or notice an increase in arousal (Goff & Smith, 2005). The model may be relevant for this study; however, it is important to consider the effect of caring for near-death experience patients, irrespective of whether the caregiver had previously experienced any traumatic event or not.

The term ecology is derived from biological science and it refers to the interrelations between organisms and their environment (Glanz, Rimer, & Viswanath, 2008). As the model of ecology evolved, the focus was not only placed on the individuals’ perceptions of their environment but further emphasised the direct effect of the environment on the behaviour (Barker, 1968). Based on the multiple levels of ecological theory, intrapersonal,
organisational, community and public service are factors that influence health and behaviour functioning in the caregiving environment (Glanz et al., 2008). It is important not only to show variations between the abovementioned levels, but also to consider how they lead to change in human behaviour (Glanz et al., 2008). Given the complexities of human experience and the outcome of the reciprocal interaction between the caregivers’ patients and their environment, a more holistic approach in understanding compassion fatigue is central within the caregiving environment.

There is a clear description of how the environment influences individual health and behaviour, and this is fundamental in the multiple levels of ecological theory (Glanz et al., 2008). However, it is also important to consider how this multilevel of ecological theory is affected by the individual behaviour (McLaren & Hawe, 2005). McLaren and Hawe (2005) looked at more linear interactions in the environment affecting the individuals’ behaviour (McLaren & Hawe, 2005), but in order to better understand the concept of compassion fatigue, one needs to look at the behavioural effect of the palliative caregivers on their environment, because it is important to understand how they perceive their experiences of compassion fatigue.

Individuals’ perspectives and experiences according to this theory are never the same. Interaction and causation are central to the ecological theory (McLaren & Hawe, 2005), as caregiving is based on complex interactions between the carer and the care recipient. Human behaviour can only be understood from the context in which it takes place; behaviour settings also exist in a broader socio-physical environment.
The basic premise of ecological thinking is that health, behaviour, and their determinants are interrelated (Salazar, Bradley, Younge, Daluga, Crosby, Lang, & DiClemente, 2010). Health promotions are influenced by ecological theory, and the same goes for any other work environment where behaviour and human outcome are influenced by their environmental structure and other determinant factors. Compassion fatigue is an unhealthy reaction to environmental stressors, therefore making the sociocultural environment of caregivers the underlying cause of this unhealthy behaviour.

With regard to the theory’s emphasis on behaviour being different from one environment to the other, this theory fits well with the aim of this study to explore compassion in the phenomenon of compassion fatigue in a hospice setting. It is therefore important to understand compassion fatigue from the environment that may influence a certain type of behaviour. To understand human behaviour, it is crucial to consider the social system that is believed to be the influence or enables that behaviour (Bronfenbrenner, 1994). In order to understand compassion fatigue and the influence of exposure to traumatic events on compassion fatigue, it is important to look at the environment believed to be influencing the experience of compassion fatigue. The environment can operate as a stressor, exerting detrimental effects on individuals’ moods, performance and physiology as a result of their exposure to uncontrollable demands, such as trauma experiences and interpersonal conflict (Bronfenbrenner, 1994).

The experiences of palliative caregivers will be evaluated carefully from the participants’ experiences to create new knowledge and even an understanding of compassion fatigue. This will create a shared grounded platform that will provide a new and common insight into the concept of compassion fatigue as experienced within the palliative care hospice.
setting. The ecological theory in this study will bring together the different experiences from different perspectives to ensure a better understanding of compassion fatigue complexities within different environments.

This theoretical discussion begins by considering palliative caregivers’ unique experiences within their environment. Palliative care, as explained by WHO (2006), is an approach that offers support to families and patients on coping with illness, death and bereavement, while integrating the psychological, spiritual and the physical care, as well as providing care and support to the professional caregiver. Within the ecological approach, palliative caregivers are exposed to their patients’ pain and suffering, making them susceptible to experiencing occupational stress. In this study, occupational stress is presented as a secondary trauma and referred to as compassion fatigue, because of a transaction between the palliative caregivers and their patients being of a complex nature (Hughes, 2009).

According to the ecological approach, individuals assign meaning to everything with which they come into contact and this meaning represents reality to them (Meyer, Moore, & Viljoen, 2003). Within this study the ecological theory fits well, as the researcher is interested in the interaction between palliative caregivers and their environment, as well as the meaning they ascribe to their experiences. It is rather important for palliative caregivers to be aware of the self and their role, their surrounding and its impact on them as caregivers (Pack, 2013).

As stated earlier in the review of literature, compassion fatigue encompasses a breaking down of the physical, psychological, interpersonal and even spiritual resources (Campbell, 2013; Coetzee & Klopper, 2010; Figley, 2002; Palomino, 2008). Key components
underpinning the ecological theory in this research include multiple and interconnected systems such as collaborative family healthcare, physiological functioning (somatic symptoms, physical effects), psychological functioning (depression, anger, sense of hope and hopelessness, trauma), relational and family systems (attachments, communication, boundaries, cohesion, adaptability) and the larger social and ecosystemic structures (supportive peer and friendships networks, workplace support structures) (Mendenhall & Berge, 2010).

According to Glanz et al. (2008), the ecological theory has been central to the health profession. It is a perspective that emphasises both the individual and contextual system and the interdependence between the two (McLaren & Hawe, 2005). The ecological approaches to health and wellbeing promotion therefore target multiple environmental influences of human health and wellbeing. When we look at the ecology of human health and wellbeing, it involves the physical, social, psychological, and the work environment as the multiple environment that is affected by compassion fatigue. All the abovementioned factors account for the caregivers’ health and wellbeing. Compassion fatigue is a phenomenon that may affect the caregivers’ daily functioning negatively, that will then affect all the abovementioned environmental factors negatively.

An ecological theory encompasses context in the broadest sense. Therefore there are multiple levels that influence the behaviour and attitude of an individual. Miller (2007) stated that the most central concept of ecological theory is adaptation, and it is an important factor in identifying the impact of compassion fatigue and being exposed to traumatic events as environmental stressors influencing the health and wellbeing of caregivers. Another factor that is important in understanding the impact of compassion
fatigue on palliative caregivers is the concept of stress. Stress can occur as a result of life experiences and it is subjective, as the same type of stress can be experienced differently within the same context (Hughes, 2009). This is applicable within this study, as each palliative caregiver is more likely to experience stress differently from the other, hence there are unique experiences that the researcher is hoping to deduce from their responses.

2.8 CONCLUSION

Compassion fatigue is a unique and complex concept that has a significant effect on caregiving professionals who have direct contact with patients or clients who experience traumatic events or who are suffering from life-threatening illnesses. The research literature gave an explanation of the causes of compassion fatigue and how it impacts on professional caregivers’ daily functioning. There was also literature on the effect of support and training on compassion fatigue. Using phenomenological study, compassion fatigue is understood by exploring palliative caregivers’ experiences of the phenomenon of compassion fatigue.
CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

The aim of this study is to contribute to the literature and insight currently existing in the psychosocial body of knowledge with reference to palliative caregiver professionals’ caring for chronically ill patients. A holistic understanding of palliative caregivers’ experiences of compassion fatigue is important to facilitate the understanding of the dynamics and the experience of compassion fatigue.

The purpose of the phenomenological approach is to illuminate the specific; to identify phenomena by how they are perceived by the research participants in a particular context. In the human sphere this normally translates into gathering ‘deep’ information and perceptions through inductive, qualitative methods such as interviews, discussions and participant observation, and representing it from the perspective of the research participant(s). Phenomenology is concerned with the study of experience from the perspective of the individual, ‘bracketing’ taken-for-granted assumptions and usual ways of perceiving. Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation of the phenomenon. As such, they are powerful tools for understanding subjective experiences, gaining insights into people’s motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom.
Phenomenological methods are particularly effective in bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore in challenging structural or normative assumptions.

A variety of methods can be used in phenomenologically-based research, including interviews, conversations, participant observation, action research, focus meetings and analyses of personal texts. If there is a general principle involved, it is that of minimum structure and maximum depth, in practice constrained by time and opportunities to strike a balance between keeping a focus on the research issues and avoiding undue influence by the researcher (Creswell, 1998). A hermeneutic phenomenological study was used for this study as the researcher aimed to interpret and describe palliative caregivers’ experiences of compassion fatigue (Van Manen, 1984). This is a suitable methodology, as the researcher wanted to provide a clear description and understanding of the palliative caregivers’ experiences of compassion fatigue.

3.2 RESEARCH DESIGN

The design to be followed in this study will be qualitative in exploring palliative caregivers’ experiences of compassion fatigue. Qualitative researchers are more likely to use in-depth interviews, life histories, case studies and participant observation, as these are the designs that involve close and personal contact with the research participants’ context. Qualitative design will be used for the following reasons.

Firstly, the use of qualitative design as an inductive process enabled the researcher to organise data into categories and to identify patterns and relationships among those categories (McMillan & Schumacher, 1993). This definition implied that meaning
emerged organically from the research context. Qualitative design is applicable to this study because compassion fatigue was defined by palliative caregivers as they experience the phenomenon within their work context. It is through the palliative caregivers’ essence of their experiences that the meaning of compassion fatigue was better described and understood.

Secondly, a qualitative design provided a rich description, and subjective experiences of compassion fatigue by palliative caregivers will be brought to the fore. It is through qualitative design that the researcher was able to interpret the complex realities of the participants’ experiences (Wiersma, 1995).

Thirdly, qualitative design is important as it allowed for the subjective involvement of the researcher in the research process, and the use of the researcher’s personal responses as an information source; this has been established as important to the research process (Creswell, 1998).

Fourthly, a hermeneutic phenomenological approach is utilised in order to obtain a comprehensive description of the palliative caregivers’ experiences of compassion fatigue. The hermeneutic phenomenological approach was a useful tool because it thrives on the creativeness of the description and analysis of participants’ experiences, and it will allow the researcher to identify different perspectives from the interviews (Mouton, 2002).

Lastly, by utilising qualitative design, allowed for the flexibility to elaborate further and tailor subsequent conversations to information that the participants provided (Creswell,
Qualitative design appropriately was suitable for this study in that it allowed for the enquiry on the experiences of caring for chronically ill patients.

Patton (2002) suggests that the key issue of the phenomenological research design is the meaning, structure, and essence of the lived experience of the studied phenomenon by a group of individuals or one individual. In phenomenological research, the aim is to get a deeper understanding of the meaning that research participants ascribe to the phenomenon of interest. Knowledge in phenomenological research is treated as a social construction, which is not complete; therefore, the truth is relative (Boss, Dahl, & Kaplan, 1996). The meaning of a phenomenon cannot be interpreted the same in a group of individuals, and another assumption stated by Palomino (2008) is that situations may have different meanings to different individuals within a group. Language in phenomenological research is crucial, because it is the primary symbol that is used for interaction to better understand the unique meaning of the phenomenon or situation by individuals within that group.

The origin of phenomenology can be traced back to Kant, Hegel. Vandenberg (1997, p. 11) regards Husserl as “the fountainhead of phenomenology in the twentieth century”. It is argued that people can be certain about how things appear in, or present themselves to, their consciousness (Eagleton, 1983; Fouche, 1993). To arrive at certainty, anything outside the immediate experience must be ignored, and in this way the external world is reduced to the contents of personal consciousness. Realities are thus treated as pure ‘phenomena’ and the only absolute data from where to begin. Husserl named his philosophical method ‘phenomenology’, the science of pure ‘phenomena’ (Eagleton, 1983, p. 55).
The research value of qualitative studies is based on the participants’ responses in context to the research questions; as such, the issue of generalisation of the research finding needs to be explored. The rationale behind the choice of phenomenological research was that it will help to identify how palliative caregivers experience compassion fatigue and how they are affected by constant exposure to patients’ pain and suffering in a hospice setting. This information will be identified through inductive, qualitative methods such as focus group discussions.

For Giorgi (1985), the operative word in phenomenological research is ‘describe’. The aim of the researcher was to describe as accurately as possible the phenomenon, refraining from any pre-given framework, but remaining true to the facts. Hycner (1999, pp. 143-144) states that “there is an appropriate reluctance on the part of phenomenologists to focus too much on specific steps”. He goes on to say that one cannot impose method on a phenomenon “since that would do a great injustice to the integrity of that phenomenon”. This supports the intention and purpose of this research study at the outset (preliminary focus), in gathering data regarding the perspectives of research participants about compassion fatigue as a phenomenon of interest.

According to Terre Blanche, Durrheim and Kelly (2006), knowledge about humans is not possible without describing the human experience as lived and defined by the individuals themselves. The researcher described the subjective experiences of participants based on the reflections and interpretations of the research participants’ stories.
3.2.1 Theoretical paradigm

According to Lincoln and Guba (1985), a paradigm represents a belief system that links the researcher to a particular worldview. For this qualitative study, the hermeneutic approach was appropriate as I wanted to explore the experiences of palliative caregivers as they experience compassion fatigue in the hospice environment. The hermeneutical approach enables the participants to construct their own realities through reflection and interpretation (Ponterotto, 2005). The hermeneutic approach is directed at explaining human experiences of the phenomena of interest, creating multiple and equally valid realities (Ponterotto, 2005), making it important for the researcher to interact with the participants’ order to understand their lived experiences of compassion fatigue. Husserl saw phenomenology as a way of reaching true meaning through penetrating deeper and deeper into reality (Van Manen, 1984). The ultimate goal of this research was to rely on the participants’ views of the phenomenon or situation being studied, enabling the researcher to reach an even deeper meaning of the participants’ reality (Cresswell, 2003). This has led to the researcher using broad and general questions to enable the participants to construct their own meaning of the situation.

The approach that the researcher took was to be a co-creator of meaning by interacting with palliative caregivers with the aim of accomplishing a deeper understanding of the meaning and experiences that palliative caregivers bring to the fore. The literature review has enabled the researcher to know and understand compassion fatigue from the perspective of different authors such as Abendroth and Flannery (2006), Coetzee and Klopper (2010b), Day and Anderson (2011), and Sabo (2008), but the research participants brought a whole new meaning to and perspective of the phenomenon. This was achieved
from participants’ descriptions of their unique experiences and meaning they have of compassion fatigue.

3.3 RESEARCH PARTICIPANTS

Research participants for this study were palliative caregivers within a hospice setting. According to Hycner (1999), the phenomenon dictates the sampling method, including the type of participants to be used in a study. The palliative hospice that the researcher identified for this study was Bophelong Community Hospice. This particular palliative hospice was chosen on the basis of it being within the Tshwane District in the Gauteng Province and that it provides palliative care for terminally ill patients. A letter of request to conduct a study was sent to the organisation to obtain permission to conduct a study in the hospice. Participants had a choice of whether or not they wanted to take part in the study.

The first criterion was the participant’s service period. The participants were expected to have been working as palliative caregivers for a minimum of two years. Period of service was important, as it suggested that those particular palliative caregivers have been exposed to trauma and pain that is experienced by their patients and it was also expected that they would be able to provide adequate information in order to better understand compassion fatigue as the phenomenon that is being investigated. The second criterion was their age; the participants had to be over the age of twenty years. This set of participants was chosen because of their shared experience of being caregivers for chronically or terminally ill patients.

The main emphasis of qualitative research is not the number of participants involved in the study, but rather the richness, quantity, quality, and credibility of responses that were able
to address the research question (Patton, 2002). A minimum of ten participants were interviewed. The participants were interviewed until there was no new data or insight that came out of the interviews. The importance of interviewing until saturation is reached is that the richness and credibility of findings were assured (Creswell, 1998).

3.4 DATA COLLECTION

The data collection method used in this study was semi-structured interviews with palliative caregivers as participants in this research. The importance of the self as an instrument in phenomenological research was emphasised by Ely (1991) and Patton (2002). The researcher’s awareness of herself as the primary instrument of data gathering, strengthened the reliability of the data-gathering process. The first reason for using semi-structured interviews was that they are flexible enough to allow the researcher to follow up on interesting issues that may arise and that might not currently be considered significant.

The initial phenomenological question is: What are the experiences of palliative caregivers of compassion fatigue when caring for chronically ill patients in a hospice setting?

Subsequent questions that followed included, but were not limited to:

- Can you describe your personal experience when your caregiving responsibilities conflict with your responsibilities for your family?
- Can you describe how you feel when caring for a patient who is near the end of life?
- Can you describe your relationship with your patients?
• Can you describe how your social life has changed from before being employed as a palliative caregiver and after you have been employed as a palliative caregiver?

• Describe any major sacrifices that you have had to make to help a patient and how they have affected you.

• How have your experiences as a caregiver affected your life?

It is suggested by Smith and Osborn (2003) that the interview in a semi-structured interview begins with a central question. In this study, semi-structured interviews guided the participants to start talking about a particular topic (compassion fatigue). Secondly, this method facilitated the supply of a frame of reference for participants’ answers, but put a minimum restraint on the answers and their expression (Kerlinger, 1986).

Thirdly, this process allowed for a lot of probing and the responses were unique for each individual, in that right from the opening question, the following question was different for each participant. By probing the clarity of the important aspects with regard to their experiences of compassion fatigue by each participant, responses were clarified.

Lastly, semi-structured interviews were effective in revealing more about the participants’ personal views, beliefs and attitude towards the phenomenon in question. This has allowed the researcher to explore similarities and differences expressed by the palliative caregivers.

The interviews were conducted in English, but the participants were given the freedom to respond in the language of their choice. With the participants’ signed consent, the interviews were audio-recorded. Due to the participants being given a choice of responding in the language of their choice, the audio responses were translated into English and
translated back into the respondent’s language of choice. This ensured that the participant’s point of view was not lost during the translation. However, throughout the interviews, besides the audio-recording of the participants, the researcher took notes, and asked questions in order to achieve a better understanding of the situation and the participants’ thoughts about their experiences of compassion fatigue as a phenomenon of interest.

Creswell (2003) identified debriefing as an important method used to alter the participants’ mental state to ensure that the participants were comfortable about having participated in the research interviews. During debriefing time, the participants were informed of the purpose of the study and the practical implications of the research study.

3.5 **PROCEDURE**

Ethical clearance was received from the University of South Africa (UNISA). Consent was also obtained from the managers or custodians of the hospice before consent was received from prospective participants. A letter of request to conduct a study, together with a brief outline of the research proposal, was sent to Bophelong Community Hospice. A meeting with the custodians was arranged to provide them with the description of the research to be conducted. Another meeting was arranged with all prospective participants providing them with the description of the research and to explain the ethical issues related to the research, and they were given consent forms to complete if they were interested in participating in the study. The interviews were reciprocal, meaning both the researcher and the participants engaged in the dialogue.

The interviews lasted 40 to 50 minutes each and an audiotape was used to record the interviews, which was later transcribed. Being a phenomenological study, great value
was placed on the participants’ personal internal world and gaining an understanding of their experiences and the meaning they ascribed to the phenomenon of compassion fatigue. The researcher focused on what the participants experienced and got the participants to describe the lived experiences in a language as free from the constructs of the intellect and society as possible; this is one form of bracketing. There is also a second form of bracketing, which, according to Miller and Crabtree (1999), is about the researcher bracketing her/his own preconceptions and entering into the individual’s life world and using the self as an experiencing interpreter.

The researcher had no influence on the participants’ responses, but also attempted to see the phenomenon in a new perspective by simply viewing it in a new light rather than as a known or familiar phenomenon. That way the researcher had no preconceived notions about the concept of compassion fatigue.

3.6 DATA ANALYSIS

In this study, data was analysed using thematic data analysis. The researcher in this study used Giorgi’s phenomenological model (1985) to analyse data. According to Giorgi (1985), thematic analysis aims to establish categories by going through the concrete expressions, and not by abstractions and assumptions. Data was analysed by discovering patterns, coherent themes, meaningful categories and new ideas, and in general uncovering a better understanding of the phenomenon being studied. This involved reading each interview transcript carefully in order for the researcher to develop a general knowledge of the phenomenon and to become familiar with the language used by the participants. The researcher, as an instrument of data collection, was immersed in the natural setting of
palliative caregivers as they described their experiences, without the researcher having a pre-determined framework (Kruger, 1988).

During data analysis in qualitative design, there is a need for the researcher to have a complete understanding of the phenomenon being investigated (Giorgi, 1985). This study involved several stages of the thematic analysis. In the first stage, information was collected from interviews, transcribed and printed in order to facilitate reading through the interviews carefully to develop a general knowledge and understanding of the phenomenon from the palliative caregivers’ point of view, and also to become familiar with the language that was used by the participants (Palomino, 2008).

In the second stage, after the researcher has gained a general idea of the phenomenon’s pattern of data, the data was broken into smaller units of meaning that share similar themes. The units of meaning were then categorised to capture the experiences of palliative caregivers. Here the similarities and differences between groups of data emerged, where the researcher had identified whether there was a consensus or conflict in the meaning that participants ascribed to the phenomenon or whether there were similarities or difference in participants’ experience of the phenomenon (Miller & Crabtree, 1999).

During the third stage, the themes were studied with a fresh view to explore them more closely in order to capture finer nuances and to revise the coding (Terre Blanche et al., 2006).

In the fourth stage, themes were described in such a way that they captured the phenomenon as experienced by the participants. The researcher integrated the insight
gained from the transformed units of meaning and themes to develop a consistent description of events (Giorgi, 1985).

Lastly, the concept of bracketing was employed in this study: not allowing the researcher’s personal view, presuppositions or personal meaning to enter the unique world of the participants (Creswell, 1998; Groenewald, 2004; Moustakas, 1994).

In the initial analysis, the researcher repeatedly listened to the recordings of the interviews. She then read and re-read the transcripts. From each transcript each response was carefully studied with the question of “what does this reveal about palliative caregivers’ experiences of compassion fatigue”, selecting and highlighting statements, sentences and quotations that helped me to understand how the participants experienced compassion fatigue.

The common keywords and concepts were identified and grouped together, while isolating sub-themes from the key themes. Alongside each transcript, codes were written down, changing many times before there was clarity in code patterns. This enabled the researcher to understand the text with reference to the literature (Groenewald, 2004).

3.7 ETHICAL ISSUES

Ethical clearance was obtained from the University of South Africa (UNISA). Consent was obtained from the managers or custodians of the hospice before consent was received from the prospective participants, as indicated above. Stommel and Wills (2004) define informed consent as a disclosure statement to be signed by each participant that contains a clear account of all the risks and benefits involved in the participation in a particular research study. The informed consent document communicates to the prospective research
subjects the purpose, procedures including time commitment of the subject, risks and benefits of the study, and the confidentiality of their information. The signed informed consent form will be retained for four years to serve as proof that the participants understood and agreed to participate in the research.

A meeting was arranged with the key roleplayers to explain and brief them on the nature and purpose of the study. Two consent forms were given to prospective participants, one for agreeing to participate in the study and the other one for agreeing for interviews to be tape-recorded. All the copies of the consent forms were linked to the record of the findings. The participants were provided assurance of their anonymity and confidentiality.

A clear description of the date and venue of the interview was provided to them in writing and they were given the right to amend or make changes to the dates or times as it suited them, but within a particular timeframe. All participants were assured that no personal information was to be revealed. No names were mentioned in any report nor attached to the recorded or transcribed interviews. Only pseudonyms were used in an effort to maintain anonymity. This study did not aim to cause the participants any harm. Interviews were audio-recorded and later transcribed; the audio-tapes and the transcribed data were kept locked up by the researcher. Only the researcher had access to the raw data. The participants will have access to the final report.

The raw data was be stored in an Excel file maintained on a password-protected memory data storage device. Data was coded to protect confidentiality. Following acceptance of the completed dissertation and after the four years have expired; the Excel file will be erased from the memory data storage device. The transcripts, including consent forms and the
instrument paper, will be kept in a sealed envelope and stored in a locked cabinet, and after four years have elapsed, these hard copies will be shredded as well to protect the participants’ identity information.

An arrangement was made with the senior sister on duty or the manager for a registered counsellor to be present on the days that the interviews took place. Although they were not present in the interview room, they were present at the hospice premises as they could assist in situations where the participants may have experienced evoked emotions with regard to previous traumatic memories or experiences. The voluntary nature of participation was also made clear to participants and that they were free to withdraw if at any point they felt they no longer wanted to take part in the research, with no consequences whatsoever.

3.8 TRUSTWORTHINESS

For qualitative studies, it is important for a study to have credibility. According to Lincoln and Guba (1985), ensuring credibility is one of most important factors in establishing trustworthiness. Sandelowski (1986) suggests that a qualitative study is credible when it presents accurate descriptions or interpretations of human experiences that people who also share that experience would immediately recognise from the descriptions. In a qualitative study, the main goal is not to generalise the findings, but to represent participants’ experiences and perceptions accurately, coming from their rich descriptions in a truthful manner (Burns & Grove, 1997). Another aspect of ensuring trustworthiness of the study is for the researcher to bracket her- or himself from the study; the focus will therefore be on the insider’s (research participant’s) perspective (Mouton & Marais, 1992).
Bracketing is important during data collection and transcribing of the data. The participants received a copy of the transcribed text to validate that it reflected their perspectives regarding the phenomenon that was studied, as this had ensured that the findings were trustworthy. According to Creswell (2003), validity plays a significant role in a qualitative study in that it is a powerful source used to determine the accuracy of the study’s findings.

It is important for the researcher to document her or his own personal feelings, observations and reflections to consider when writing a final report. The researcher was open to critique and not only confirmed information about the research. Lincoln and Guba (1985) recommend prolonged engagement between the investigator and the participants in order both for the former to gain an adequate understanding of an organisation and to establish a relationship of trust between the parties. It was therefore important to spend some time, informally, with the participants before the actual interviews could begin. The researcher attended two workshops and a briefing meeting prior to the interviews. This allowed the participants to feel free around the researcher, as they were familiar with her.

Credibility was enhanced within the interviewing process. The reframing of questions, repetition of questions, or expansion of questions on different occasions, are ways in which to increase credibility (May, 1989). It was therefore important to probe the responses of the participants in such detail in order to ensure a thorough understanding of their responses. In general, according to Trochim (2006), credibility in qualitative research means that the results of a study are believable or credible from the point of view of the research participant. Since each participant’s perspective of the phenomenon is what constitutes qualitative research, the participant was the only person who was able to ensure the
credibility of the results. It was therefore crucial for the researcher to probe the participants on their responses before reporting on the findings.

Transferability means the degree to which the results of qualitative research can be generalised or transferred to other settings. Transferability of findings is crucial in qualitative study, meaning that the findings will be useful and applicable to others in a similar situation, with similar research questions (Bloor, 1997; Lincoln & Guba, 1985). Confirmability may be arrived at if the study will be administered in another province, on participants who share similar characteristics and arrive at findings that are similar to the first study (Lincoln & Guba, 1985).

The researcher disclosed her status and position in terms of the field of study, the experience and skills she has and the university that she is affiliated with, to ensure that the participants responded with depth and authenticity. The role of the researcher was to ensure transferability by providing a thorough description of the context in which the research took place and the assumptions made regarding the study.

Another concept that is important to consider in qualitative studies is dependability. When applied to qualitative research, the emphasis is placed on the reporting of every change in the context in which the study takes place. The research itself described the changes and the way the changes affected the researcher’s approach to the study. Confirmability refers to the degree to which the results can be confirmed or corroborated by other researchers.

The qualitative approach appropriately suits the nature of the inquiry with regard to the experience of caring for chronically ill patients as lived by the respondents. The qualitative
approach gave the participants the freedom to explore and express their experiences without restrictions characteristic of quantitative approaches.

Another reason for using this method was that the qualitative research approach was flexible to address questions that could not easily be addressed or captured with a quantitative approach. According to Barker, Pistrang and Elliott (2005), one great advantage of the qualitative approach is that the researcher may find issues or phenomena which were not intentionally planned or expected. It has been proposed that in qualitative research, the collection of data must provide evidence for the perspective under investigation, which provided an opportunity to explore the themes that emerged throughout the data and identified those phenomena that emerged in the manuscript.

3.9 EXPECTED FINDINGS

Patton (2002) states that the nature of qualitative research is to find out or describe what the phenomenon looks like and feels like in the world and experiences of the participant. As was anticipated, the experiences described by caregivers contained commonalities and differences. Furthermore, the fundamental experience of caring for chronically ill patients was formulated. A better understanding of the dynamics is expected to be helpful for caregivers, counsellors, nurses and other helping professionals in the development of interventions, programmes and services that could meet the unique needs of the caregivers.

3.10 CONCLUSION

This chapter discussed the research design and methodology that were followed. Further, data collection and analysis were discussed, along with the relevant ethical considerations. The next chapter of this study focuses on the findings and analysis.
CHAPTER 4

FINDINGS AND ANALYSIS

4.1 INTRODUCTION

In this chapter the researcher considered the results of the study which were arrived at using the methods described in Chapter 3, that aimed to extract the units of meaning within a psychological perspective and within the researched phenomenon of compassion fatigue. These meaning units have been conceptualised by the researcher after reading through all the interviews and gaining an overview of the text as a whole. Once the units of meaning have been delineated, the researcher synthesised all the transformed meaning of units into themes and consistent statements that described the participants’ experiences of the phenomenon of compassion fatigue.
4.2 RESULTS OBTAINED FROM THE PARTICIPANTS

4.2.1 Demographics of the participants

This research included seven (7) participants who are palliative caregivers in a hospice. All seven participants are females, ranging in age from 22 to 50 years. The participants’ demographic details are presented in Table 4.1. The names of all participants are pseudonyms in order to maintain anonymity.
Table 4.1: Demographics of participants

<table>
<thead>
<tr>
<th>Name*</th>
<th>Age</th>
<th>Years of Experience</th>
<th>Marital Status</th>
<th>Number of Children/Dependants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Malebo</td>
<td>36 years</td>
<td>2 years</td>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>2. Nomsa</td>
<td>29 years</td>
<td>7 years</td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>3. Lerato</td>
<td>49 years</td>
<td>5 years</td>
<td>Widow</td>
<td>3</td>
</tr>
<tr>
<td>4. Rose</td>
<td>39 years</td>
<td>4 years</td>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td>5. Julia</td>
<td>24 years</td>
<td>2 years</td>
<td>Single</td>
<td>0</td>
</tr>
<tr>
<td>6. Mmatshepho</td>
<td>44 years</td>
<td>3 years</td>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td>7. Gugu</td>
<td>34 years</td>
<td>7 years</td>
<td>Single</td>
<td>0</td>
</tr>
</tbody>
</table>

* Not their real names

Each interview was completed in 35 to 40 minutes. Giorgi’s (1985) phenomenological model is suited to this study because of the nature of the research model, allowing the gathering of themes and structures that produce descriptions that lead to the understanding of compassion fatigue as experienced by palliative caregivers.

All the interviews were audio-recorded and transcribed to enable the researcher to produce themes leading to the understanding of compassion fatigue as experienced by each participant.
The seven (7) palliative caregivers interviewed work day and night shifts in a hospice setting. The caregivers interviewed are on duty for five days and off duty two days per week on a day shift; on a night shift they are on duty seven days and seven days off duty.

From the researcher's observation, the participants appeared to be at ease and displayed no tension or anxiety during the interviews. This may be due to the researcher’s two-day visit prior to the interviews and attending the workshop on ‘caring for dementia patients’. The participants were familiar with the researcher and that had a positive impact, as they were more relaxed and not treating the researcher as an unknown or unfamiliar person. That, in turn, enabled the researcher to be familiarised with the staff, their daily routine and the overall experience of a hospice context.

The research participants had a challenge in thoroughly verbalising their experiences of compassion fatigue. Firstly, this may be due to the different roles they have to play in different situations and circumstances within a hospice context. Secondly, it may be because they are not familiar with the concept of compassion fatigue. Given the broad contextual, environmental factors, and the unfamiliarity of compassion fatigue as a concept of interest, the caregivers had different experiences and presentations of compassion fatigue. The themes identified by the researcher have the purpose of providing the reader with a broad perspective of how caregivers experience compassion fatigue. The participants’ naive descriptions were kept, but the formulated units of meaning were transformed from concrete expressions of the researcher’s psychological phenomenological interpretation. A more comprehensive picture of the caregivers’ experiences of compassion fatigue was developed, taking into account the four themes that
are presented to provide a fundamental understanding of the experience and impact that compassion fatigue has on palliative caregivers.

4.2.2 Themes presentation

After a thorough reading of the transcriptions, a cluster of themes was identified. The interview transcripts produced significant statements that were extracted from the analysis. These significant statements included complete sentences and a combination of statements that captured one or more constituents.

The first theme that was identified by the researcher was that the personal wellness of participants is affected because of them being overlyinvolved with their patients’ lives and wellbeing, and not being aware of the negative effects their over-involvement has on their emotional wellness. Compassion fatigue, as experienced by the participants, therefore resulted in them experiencing self-blame and feelings of guilt, helplessness, loss of interest, and feeling trapped in their profession.

The second theme identified by the researcher is the inability to balance personal and work relationships. The sub-themes reported by the participants are an exaggerated sense of responsibility, experiences of compassion fatigue in marriage and family life, experiences of compassion fatigue in social life, and unresponsiveness.

The third theme is the participants’ experiences of compassion fatigue translated into physical discomfort. The participants reported experiencing excessive physical exhaustion, headaches, and prominent sleep disturbances.
The fourth theme is the experiences of compassion fatigue translated into a lack of spiritual awareness. The sub-theme identified is spiritual effect.

4.2.2.1 Theme 1: The experiences of compassion fatigue on the participants’ emotional wellbeing

The participants in this study are overly involved with their patients, to a point where their personal wellness is affected. Here compassion for near end-of-life patients is the driving force behind palliative caregivers’ basic desire to help their patients (Pearlman & Saakvitne, 1995), therefore becoming overly involved with their patients due to the unrealistic high expectations they put on themselves with regard to ensuring the healing and wellbeing of their patients, and thus being unable to balance their professional and personal lives (Sherman, 2004).

The following statements serve the purpose of providing the reader with a broad perspective of how caregivers are affected by the experience of compassion fatigue. The majority of the participants reported experiencing self-blame and feelings of guilt, helplessness, and feeling trapped, and one of the participants reported being unresponsive to patients’ pain and suffering. With that being said, one of the progressive and cumulative processes that evolve from compassion stress that later lead to compassion fatigue is unresponsiveness to patients’ pain, callousness and an indifference towards patients’ pain and suffering (Coetzee & Klopper, 2010). Some of the participants displayed all the above indicative signs and, having been involved in caregiving for more than two years, it seems that their previous level of compassionate functioning is unattainable.
Self-blame and guilt

High levels of unrealistic expectations by caregivers have resulted in patterns of self-blame and feelings of responsibility when they lose a patient or even when the patient is in inconsolable pain (Sherman, 2004). This is a contributing factor to caregivers becoming vulnerable to occupational stress. As the patient’s health deteriorates or the patient is dying, caregivers go through grief, guilt and even resentment often related to caregivers’ experiences of strain (Day & Anderson, 2011). This may be due to caregivers setting their expectations of positive outcomes for patients very high, therefore resulting in caregivers’ self-blame and feeling that they have failed their patients (Solomon, 2014).

Below are the participants’ remarks that support the above statement on their experiences of self-blame, guilt and feeling responsible for the patients’ pain, or even death, as a result of compassion fatigue. Statements such as “I feel like it’s my responsibility to make sure that they get better”, “I blame myself” and “I just feel so bad… maybe even responsible”, clearly indicate that the participants hold assumptions that they are personally responsible for their patients’ wellbeing.

Malebo stated:

There are times where I feel that there should be something more that I can do or maybe could have done to make sure the patient have or even had a little more time or even felt lesser pain, if not complete recovery. I just feel so bad… maybe even responsible…
Nomsa commented:

I sometimes second-guess myself wondering if I am capable of providing the best possible care. I really don’t know, only God knows. But I cannot help but constantly wonder and feeling that maybe I don’t do enough.

Lerato stated:

When I am on my day off I do worry about them. It’s not easy knowing that there is someone sick and is dependent on you to help them and you cannot be there for them. Even if it’s only for a day or two you just feel like you have abandoned them…

When I lose a patient and I am not there by that time I just feel like I failed them somehow… and I can only blame myself (Lerato).

Rose commented:

If I lose a patient I always wonder if I have provided the best possible care for the patient, I just feel like it’s my responsibility to make sure that they get better, but when they don’t I just carry that with me for days, wondering.

Julia described that:

I feel a great loss when I lose a patient. My patients become part of my life. They depend on me and they believe in me, so when I lose them I tend to blame myself or feel a sense of guilt in that maybe I should have done more to help them or even ease the pain. It’s stressful at times and I end up losing hope.
Helplessness

Feelings of failure and loss of motivation lower the caregivers’ sense of achievement regarding their service to the patients’ needs (Figley, 2002, Palomino, 2008). According to Palomino (2008), helplessness occurs on the basis that a caregiver experiences a sense of being out of control or unable to do something to change the loved one’s or patient’s condition. A negative emotion has a detrimental effect on the caregivers’ compassion comfort. Thus their work environment and experiences can function as a stressor, exerting detrimental effects on the individual’s moods. Hence some participants reported feeling helpless when they realise there was only so much they could do for their patients. The participants felt out of control of their patients’ recovery and that has left some of them feeling that they were not doing enough. Despite the participants’ efforts to provide care, ease patients’ pain and discomfort, a patient loss increased their levels of stress and loss motivation, therefore experiencing higher compassion discomfort that may later develop into compassion fatigue.

Malebo commented:

It is not a good experience watching a patient suffering like that and even going through pain while you are and knowing that there is only so much you can do for them, it is saddening. It is sad because a patient will come in very weak and you nurse them until you can tell that they are actually gaining a bit of strength, but unexpectedly they pass away… you don’t know how sad it is standing there and watching this patients.
Nomsa stated:

I feel like a failure after losing a patient. I kind of loose the motivation to care for the next patient, especially if they are not doing too well, because you already know that you may lose them sooner or later and there is really nothing one can do.

Rose reported:

I feel so helpless after a patient loss. I start to approach other patients with anxiety and often it takes days before I can feel like my normal self. Because I don’t know what is going to happen with the patient, I feel like I don’t have much control on my work and patients and I feel like a failure, it is like you are failing your patients. It becomes difficult to regain the hope of recovery with the next patient.

Julia stated:

When a patient takes a turn for the worse or even pass, it does hurt and I get so unmotivated and experience low energy level. You start to question whether your efforts were enough or even worth. You know! All hope is lost at that moment.

Loss of interest

Compassion fatigue has been reported to have the ability to reduce caregivers’ capacity and interest for caring and bearing patients’ suffering. Gugu’s statement of “There are times where I just feel like I shouldn’t give my all or even go all out” indicates that she is losing interest in her work. This is evidence of the development of compassion fatigue. Some of the participants have reported that witnessing terminally ill and near end-of-life patients has put pressure on them emotionally, causing them to experience high levels of stress. Exposure to such prolonged emotional stress accumulated overtime may take a toll
on caregivers’ pleasure of giving care in their profession. Consistent with literature, the participants experienced loss of interest in their work, and emotionally disengaged from the patients (Day & Anderson, 2011). This decrease of interest may result in caregivers not being able to provide care to the best of their ability (Day & Anderson, 2011; Sabo, 2008).

Lerato stated:

After losing a patient I just feel emotionally tired to a point that I just want to rest and do nothing.

Rose, on the other hand, stated:

When I lose a patient I feel like a failure and I lose the energy to care for the next patient, especially if they are not doing too well, because I already know that I may lose them sooner or later and that put a strain on me.

Julia commented:

The most negative thing is just witnessing so much pain each day. I end up questioning whether I have chosen the right career, and sometimes feeling that I should just give up and change careers.

Mmatshepho reported:

It is the unknown that always keep me on the edge and fearful, which then stress me a lot at work and it is emotionally draining. It will then be difficult for me to come to work and function to the best of my ability. If I had a choice I wouldn’t be here.
Gugu reported:

I am the happiest when I am on my day off, I just relax and not worry about bathing, caring, feeding or cleaning after anyone. There are times where I just feel like I shouldn’t give my all or even go all out, you know doing the same thing over and over and for what? …We still lose this patients anyway. All for nothing…

Feeling trapped

Due to the unemployment rate in South Africa, some of the participants reported not having many career options or opportunities. Caregiving was therefore the only option for them to have some economic or financial stability. This has led to some of the participants questioning whether or not they have made the right career choices. Feeling trapped is the constituent that describes the sense of being an emotional and physical hostage of others’ conditions (Palomino, 2008). The participants have discussed the feeling of not having many options; some have even stated the need to work in a less stressful and traumatic environment.

Nomsa explained:

This is what I decided to do therefore I had to adapt to the challenges, though it’s not easy. Only wish I have other opportunities… Which I don’t of course.

Lerato stated:

I believe this is one of the most difficult jobs, because people now look up to you to care for them. I only wish that I didn’t have to witness death like this.
Julia expressed that:

I sometimes feel trapped in a circle of life and death. Either way I am going to feel patients’ pain and suffering, whether I lose the patient or not it is still painful… how does one ignore such things?

4.2.2.2 Theme 2: The second theme is the translation of participants’ experiences of compassion fatigue in their personal and work relationships

Caregivers work for long hours and they are prone to physical and mental exhaustion. Their family conditions and circumstances become difficult to manage. The participants have expressed awareness and mostly a concern of experiencing the negative effects of compassion fatigue on their interpersonal and work relationships. A high level of compassion discomfort has affected the way the participants relate to family, friends, patients and social life. The participants in this research found it difficult to balance work and personal lives. They reported not having enough time with family, which has affected their family relationships. Some have reported loss of energy or motivation to participate in activities outside their workplace, resulting in stressful family conditions that may further influence caregivers’ vulnerability to compassion stress that may develop into compassion fatigue.

These findings in this research indicated that due to high levels of compassion fatigue, some of the participants isolated themselves from their family members to avoid arguments. In Palomino’s (2008) findings, this was a positive coping mechanism that was used to cope with compassion fatigue, to avoid highly anxious interactions between family members. The findings in this research revealed that the caregivers are distancing
themselves due to the high level of anxiety and distress, therefore creating friction and resulting in family members feeling neglected.

**Exaggerated sense of responsibility**

Caregivers who sacrifice more have been found to be more vulnerable to compassion fatigue. This is a reflection of an unhealthy level of empathy, where caregivers may put their patients’ needs before their own or even going beyond caregiving. The participants have reported taking the role of family members by making the necessary provisions for patients, where needed. An unhealthy level of compassion, coupled with prolonged exposure to terminally ill and near end-of-life patients, is regarded as a risk factor for compassion fatigue (Sabo, 2011). The participants in this study have shown to care about their patients more than about themselves or family members. The participants have reported sacrificing not only valuable time with family and friends, but financially as well. Participants reported being overly empathetic and being overwhelmed by their patients’ conditions and state of health, so that it causes them distress and it deliberately increases their workload. Some of the participants reported that it was their responsibility to provide an all-round care and support for their patients. Consistent with the literature reviewed earlier, the identifying feature of compassion fatigue is feeling so overly responsible for others’ pain that it is overwhelmingly exhausting.

Lerato said:

The idea is to make the lives of my patients very comfortable and that they don’t feel neglected. That is why I feel it is my responsibility to make sure that they have the basic things or necessities that will make their lives easy, especially those that their family members don’t visit as often as they should.
There are those patients that are not in a good condition that when I am not at work I just worry about them to a point that I will constantly worry about how they are doing. I realised that it is just too much for me (Lerato).

Malebo described:

At times you find a patient not having toiletries and I will find myself taking what I have from home to provide for the patient or even buying what they need from my own pocket. Even though I don’t get paid a lot, where I see a need, I have to make a sacrifice.

Nomsa described:

I often ask myself if I am sacrificing spending time with my family, especially my kids for this work, because I spend more hours here caring for my patients. I would like to believe that they need me as much as my family does… and I have to care for them as much.

… I totally care for my patients… or else there won’t be anyone who cares for them (Nomsa).

Malebo stated:

I sometimes worry about my patients when I am on leave and I find myself calling the hospice to find out how my patients are doing. I guess I just worry too much, because it is painful when you get back at work only to find that you have lost a patient.
Experiences of compassion fatigue on marriage and family life

Caregivers’ stress and emotional confusion that result from the needs of family members can vicariously impact the caregivers’ primary and secondary relationships (Palomino, 2008). According to Day and Anderson (2011), caregivers distanced themselves from their patients and family members. The participants’ responses showed that compassion fatigue has affected their relationships with their families. As stated by Edwards and Karnilowicz (2013), the relationships between the caregiver, patient, family system and social system are important to better understand how compassion fatigue is experienced by the caregiving professionals. Some of the participants mentioned how memories or thoughts about certain patients or situations at work provoked emotional responses such as anger, irritability, and a lack of patience towards family members or situations (Sudeck, 2012). This may have an impact on the caregivers’ ability to rest and focus on their family and their social lives. It is therefore important to consider family and social relationships to better understand the experiences of palliative caregivers of compassion fatigue.

Rose is experiencing irritability because of compassion fatigue and Lerato, on the other hand, finds herself having more arguments or disagreements with her child. Consistent with the previous literature, the participants’ experiences of compassion fatigue are negatively affecting their family relationships.

Rose stated that:

My work takes up all my energy and so it becomes difficult to put more energy into anything else especially my family. How I wish I could do all and make everyone happy but I can’t and it is very worrying especially for the wellbeing of my family.
As a mother I know I am responsible for my family’s wellbeing, but those not pulling any weight and assisting me with some of the chores and show responsibility irritate me a lot. I end up resorting to shouting and screaming which also irritates them. I really don’t know what the solution is, but I do know I am the problem. As sad as it is to say it is true (Rose).

Lerato stated:

Sometimes me and my eldest child we can argue over really petty things, and that worries me because it’s unlike her.

Rose stated:

Recently my husband and I have been arguing a lot, and I can’t tell you what exactly we argue about. I learned to just walk away. I really don’t have the energy for arguments. But even if I walk away, he will bring that issue up again in a day or two, then the argument start all over again. I am just short tempered and I know I am the main cause of all the arguments I really get irritated easily.

I don’t think that my husband understands what I have to go through on a daily basis and I expect him to be more understanding than the kids. Sometimes it makes me feel that I am on my own (Rose).

Mmatshepho described:

I remember my son once said to me “you don’t even care about us anymore, why should you worry who I hang out with”. As a mother we try to protect our kids and keep them safe, that’s all I was trying to do, because he was spending way too much
time with the wrong crowd at school. But those words are stuck with me and I felt so devastated and worried that he actually thinks that I don’t care. He actually believes I don’t care for him as much as I use to. The hours I put in work and how I get tired after those long hours, I really don’t blame him. Coming from work I just want to sleep… I will be tired and I don’t think they understand or even have an idea of the things I have to face daily…

Malebo stated:

My family gets affected by my work stress, because I have realised that when I have stable patients I can get home and not find myself loosing temper and being more patient. But when I have critically ill patients I just become impatient.

There are times where I get back from work the little one is already asleep or when I work nightshift the kids are leaving for school. Really? That’s not a healthy way of raising kids (Malebo).

Mmatshepho described:

My long hours at work are affecting the time I need to be spending with my husband, the time we spend together is just not enough. It’s even worse when I work night shift, because when I come back from work he is leaving the house. We don’t have the time to relax and just talk anymore, and that not good for our marriage.

When I am tired and overwhelmed and I get home it’s a mess I am never happy. Whenever I bring it up everybody will accuse me of nagging. They don’t understand that I cannot go to work get back tired and do house chores (Mmatshepho).
Experiences of compassion fatigue on social life

Having a social life is particularly important in ensuring that the participants find ways to prevent or cope with their stressful work environment. It has been reported by McLaren and Hawe (2005) that compassion fatigue may negatively affect the caregivers’ social functioning and participation. Some of the participants in this study revealed that they donot engage in social activities as much as they previously did. Being involved in social activities has positive accounts for the participants’ health and wellbeing. By not engaging in social and enjoyable activities may cause the participants to be isolated, withdrawn or being very negatively affected by their patients’ distress so that they lose interest in any social activities (Adler, cited in Meyer et al., 2003). The findings in this study support those of the previous literature, in that palliative caregivers in this research study are socially withdrawn due to experiences of compassion fatigue. However, one participant discussed the need to go out and enjoy socialising with other people, being only restricted by time and always being too tired. Malebo has indicated that all she wants is to be alone; she experienced distancing, where she found it difficult to connect with other people. Lerato, on the other hand, reported experiencing isolation. She does socialise but finds it difficult to socialise with people who are not palliative caregivers because she feels that no one will understand or even relate to her.

Malebo described:

I no longer have social life. And this can be due to the hours we have to work and when you have your days off I just want to be alone.
Lerato said:

My social life is mostly with my colleagues who are more of my friends and we try to have picnics, do lunches, and get our families together for a braai or something. I realised that it is actually easier to socialise with people that understand what you are going through on a daily basis.

Rose described:

To be honest I can no longer do the things that I enjoyed doing previously. I always get fined for not attending my society meetings anymore, there are family gatherings that I sometimes miss and it’s not good because these are the people that are going to support me when I need help or any sort of support. My work takes all the energy and time, it becomes difficult for me to put more energy into anything and I miss going out with my friends or even just visiting family.

Mmatshepho described:

There is just not enough time and energy to even visit your neighbour let alone friends and family. When you have a day off the family needs you and it a challenge because you have to spend more time with them when you have an opportunity, therefore you prioritise the family over relatives or friends. But to be honest I really enjoy time on my own.

Unresponsiveness

Compassion fatigue results in feelings of discomfort where there are minor variations with the caregivers’ physical, social, emotional and intellectual functioning that may negatively affect their normal or daily functioning. There are more indicative signs of compassion
fatigue, such as unresponsiveness to patients’ pain, callousness and indifference towards patients’ pain and suffering (Coetzee & Klopper, 2010). These are progressive and cumulative processes that evolve from compassion stress that later develops into compassion fatigue. The participant below reported experiencing no compassion for patients’ pain and suffering. In line with literature, unresponsiveness is one of the indicative signs of compassion fatigue by professional caregivers (Sabo, 2008). Doka et al. (1994) and Sabo (2008) reported that it is rather important for caregivers to disclose their distress, to maintain a shift from pathology of compassion fatigue to predictive factors, which is needed to allow the caregivers enough support and adequate resources to enable them to cope with compassion fatigue. One participant reported feeling indifferent when caring for terminally ill patients and she quoted that ”I am able to block off what most see as traumatic” and ”I tend to be more less shocked by others’ pain or hurt”. Her experience of compassion fatigue indicates that her ability to be compassionate has been altered. This is consistent with the literature reviewed earlier.

Gugu described:

I don’t experience much of others’ pain and suffering and I don’t know whether the way I react is my natural reaction or is due to witnessing so many people in pain or suffering in my work. I try not to get too close to them on a personal level… I just look at my role as a carer and nothing more or less. I believe I am able to block off what most see as traumatic and that way I don’t get affected at all.

What I have realised is that I tend to be more less shocked by others pain or hurt. I really don’t know whether it is because of experiencing inconsolable pain of others every day or it’s just in my nature (Gugu).
4.2.2.3 Theme 3: The experiences of compassion fatigue translated into physical discomfort

Symptoms of compassion fatigue are anything from forgetting names and words, or having a shortened attention span (Figley, 2002). More troubling physical symptoms of compassion fatigue, as reported by Figley (2002), are exhaustion, headaches, or stomach aches which are prone to occur frequently and likely to affect palliative caregivers’ level of work performance. Resistance to illnesses is low and sickness occurs more frequently when one is suffering from compassion fatigue (Figley, 2002; Joinson, 1992; Sabo, 2011.). The participants in this study reported physiological illnesses such as low energy and swollen feet (physical exhaustion), headaches, and prominent sleep disturbances that are associated with their experiences of compassion fatigue. These are physical symptoms that will lead to increased absenteeism and loss of energy or interest to perform their daily work responsibilities of caring for their patients. Emotional saturation from working under difficult circumstances and not only that, but also their long working hours, have been shown to have an effect on their physical health.

Physical exhaustion

Consistent with the literature reviewed earlier, the experiences of compassion fatigue result not only in emotional exhaustion, but physical exhaustion that may negatively affect normal day-to-day functioning. The following are statements that were reported by the participants on their physical wellbeing while experiencing compassion fatigue. Mmatshepo and Nomsa explained being physically exhausted to a point that it was not only physically uncomfortable for them, but they had no energy left in them to get home and do anything, let alone spend time with their family.
Mmatshepho described:

You know I leave home at 6:00 am, because I have to be at work by 7:00 am and by the time I get home in the evening (7:00 pm) all I want to do is sleep. I get so exhausted and my feet will be swollen because of being on our feet the whole day. You can imagine going through that for four days before you get your day off… I really get tired to a point that I cannot do anything when I get home.

Nomsa said:

There are those days that I will feel so tired and down that when I get home I just want to bath and sleep, I won’t even have the energy to sit and talk to anyone. I even learned to not sit on the couch until all I wanted to do that evening is done or else I do what I call ‘a pass-out’ by the time I wake up an hour or more is gone…

Malebo stated:

I stay with my niece but she doesn’t help me much. She is eighteen and she should be helping with the cooking and laundry. Although she helps me with my daughter, and I appreciate, it’s just not enough. I am a single parent and sometimes I feel that nobody understand what I go through and having to care at work and get home and still care. It is just strenuous on me, coming from work my feet will be swollen and still cook for them.

**Headaches**

The present research study indicated that headaches are one of the predominant factors of the experiences of compassion fatigue. Rose talked about the intensity of her headaches as
a physical effect of her experience of compassion fatigue. Rose’s statement supports previous literature in that headache is a workload- and stress-related outcome of compassion fatigue.

Rose described:

Currently I have been prescribed with strong pain medication for my headaches. I always had mild headaches as a teenager but lately they get so worse that I can’t even wake up to go to work. Yes pain meds help a lot but there is this 3 to 5 hour pain that I have to go through before I feel better. It terrifies me I even suspect there is something serious happening with me I just don’t know what.

Prominent sleep disturbances

The present research study showed that recollections and disturbing images of traumatic events are associated with compassion fatigue, where one of the participants reported having sleepless nights due to the recollection of and being preoccupied with patients’ trauma, pain and suffering. Nomsa has reported being unable to recover from the trauma she witnesses in her work environment due to experiencing sleep disturbances as an indicative sign of compassion fatigue.

Nomsa stated:

There are nights where I cannot fall asleep, my mind will be so occupied with a patient that I left in a bad state of health and I will worry all night about them… whether I will find them still alive will be a very disturbing thought. My mind will be so preoccupied with the patient and end up not resting as well as I need to, the next
day is work and I’m still tired. Believe me this can go on for days if I have critically ill patients.

**4.2.2.4 Theme 4: The experiences of compassion fatigue translated into a lack of spiritual awareness**

**Spiritual effect**

In a study to examine the relationship between the construct burnout, compassion fatigue and compassion satisfaction, Reese (2008) found that there is a statistical relationship between spirituality and compassion fatigue. This supports Robinson’s (2005) findings that spirituality is one of the issues that is reported to be influenced by compassion fatigue (Robinson, 2005). Robinson asserts that it is rather important to question whether vicarious trauma and compassion fatigue may alter caregivers’ worldview and spirituality.

The participants in this research study reported experiencing changes in religious beliefs when experiencing compassion fatigue. Nomsa has reported questioning her faith because she knows the importance of praying to the higher powers for help, but at the same time she also question God’s presence. She quoted “I just wonder and question where God is”; this indicates that she has conflicted beliefs about her faith and spirituality.

Nomsa:

Every morning when we arrive at work we hold a prayer meeting and the intention is to ask God to protect us and our patients. But when by the end of the day one or two of our patients pass or take turn for the worse I just wonder and question where God is.
4.2.3 Summary of the findings on emotional functioning

The participants were able to express feelings and emotions in a healthy manner; they expressed the following: emotional discomfort, self-blame, guilt, self-sacrifice, feelings of helplessness and hopelessness, feeling trapped and emotionally overwhelmed. In line with Campbell’s (2013) findings, palliative caregivers face a high rate of contact with traumatized patients and therefore experience behaviours and emotional responses frequently defined as compassion fatigue. The results of this study indicate that the participants have shown to be vulnerable to occupational stress, given their feelings of helplessness and hopelessness.

The findings are consistent with those of Coetzee and Klopper (2010), who conducted a concept analysis and found that compassion fatigue is not effaced in its early stages of compassion discomfort and compassion stress, but rather it is a cumulative and progressive process. The data demonstrates that there is a potentially negative emotional effect on caregiver participants.

The other most prevalent pattern among the participants was how their experiences of compassion fatigue revealed that they are emotionally exhausted and go through high levels of stress. It was found that when caregivers are in any way affected by their caregiving experiences, they tend to experience significant levels of tension and preoccupation with patients’ pain and suffering, which is one of the basic symptoms of compassion fatigue (Figley, 1995; Sabo, 2008).
4.2.4 Summary of the effects of compassion fatigue on palliative caregivers’ social functioning

The other prevalent pattern among the participants was the effect of their work experiences on their social life, and that not only their families were affected by their experiences of compassion fatigue. The findings demonstrate that there is a decreased interest in and a lack of time for social activities. According to Figley (2002) and Coetzee and Klopper (2010), one of the most common risk factors for compassion fatigue is when individuals isolate themselves from social activities and friends; this resulting from prolonged stress, physical and emotional exhaustion, therefore affecting their social functioning.

Caregivers’ quality of life is detrimentally affected and this leads to psychological symptoms. It has been reported that active participation in social life is essential to enable the caregivers to cope with stressors and to prevent compassion fatigue (Collins & Long, 2003; Figley, 2002; Yoder, 2008). Socialising and engaging in enjoyable activities may be an effective way for the caregivers to regroup their thoughts and emotions and to rejuvenate their minds and their overall physical wellbeing.

Some of the participants reported physical health problems since they became involved in the caregiving profession; they reported swollen feet, migraines, and overall physical exhaustion. These findings are consistent with Coetzee and Klopper’s (2010) and Palomino’s (2008) findings that indicate that caregivers are negatively affected, not only emotionally but also physically, that increasing the intensity of compassion discomfort leads to compassion fatigue. The most prevalent physical discomfort in this study’s findings has been physical exhaustion.
The physical effects experienced by the participants have been reported in previous research. They are physical outcomes that result from long-term involvement in situations and environments that are emotionally and physically draining (Doman, 2010). A number of researchers have been able to document the physical effects experienced by caregivers and how that may inhibit their ability to render effective service and maintaining healthy professional relationships (Collins & Long, 2003; Figley, 1995, 2002). Physical exhaustion, headaches, and prominent sleep disturbances, among other factors, appear to be the most obvious manifestations of compassion fatigue.

Contrary to Peters’ (2010) findings, professionals in helping professions feel that they do not receive enough support and services. The participants in this study highlighted that they do receive support and services that have been of great benefit to their caregiving experiences. This study’s participants discussed the benefits of counselling services that are provided in their hospice. They are well aware of and informed about the support structures that are available to them. Coping is significant in palliative care, as caregivers are constantly exposed to trauma, death and others’ inconsolable pain, making caregivers more vulnerable to long-term stress that may develop into compassion fatigue. Some of the participants reported the benefit of talking to professionals about their experiences and challenges.

Spirituality and religion have shown to have positive benefits on caregivers’ emotional state. The participants reported faith in God as a way of coping and getting through difficult times and challenges. These findings are consistent with previous research on religion and spirituality as an effective coping strategy for gaining strength and hope for themselves and their patients (Moodley, 2009; Palomino, 2008; Uren, 2009).
participants showed that their belief go beyond just medical intervention into the divine interventions.

4.2.4 Summary of the theoretical framework

According to the ecological perspective, there is a dynamic and reciprocal interaction between the organisms and their environment (McLaren & Hawe, 2005). The findings in this study revealed that caregivers’ immediate families were impacted by the caregivers’ experiences of compassion fatigue and they also faced a challenge of balancing their families with their caregivers’ role. The findings are consistent with those of previous research studies on how trauma-related stress may spread in families (Figley, 1995, 2002; Gentry, 2002; Stamm. 2010). Figley (1995, 2002) and his students coined the metaphor of ‘infection’ or ‘crossing over’ to describe how traumatic stress seemed to infect the entire family. The participants’ long hours, levels of stress, lack of energy, and preoccupation with patients’ trauma affected their communication and quality of time spent with their loved ones.

There are units of analysis that were identified in this research; they are the environment, and the participants’ adaptive response to their environment. What really takes primacy in these research findings is the evolving mutual dependence and linkage among the participants and their environments (Soubhi, 2007). From these research findings it has been evident that all the participants interviewed had unique interpretations and experiences of compassion fatigue (Becvar & Becvar, 2006). Each had a unique experience of work, family and social challenges or stress, therefore affecting the multiple dimensions of palliative caregivers’ lives and functioning. Palliative caregivers’ experiences of compassion fatigue in this regard are shaped mostly by the hospice care facility,
colleagues, patients, family members, behaviours, beliefs and knowledge. Ecological theory in this research recognises that the environment has a crucial bearing on the impact on palliative caregivers of trauma beyond the physiological and into behavioural, social and existential realms (Adamson, 2005).

4.3 CONCLUSION

This chapter presented research findings and an overview of the findings with regard to palliative caregivers’ experiences of compassion fatigue at Bophelong Community Care Centre. Data was analysed through thematic content analysis. The findings were based on the four relational themes (i.e. the experiences of compassion fatigue of palliative caregivers’ emotional wellbeing, personal and work relationships, physical discomfort, and spiritual awareness) that describe the experiences of palliative caregivers of compassion fatigue in a hospice setting, thus providing a holistic understanding of the complexity of compassion fatigue in a palliative care hospice setting. Based on these research findings, Chapter 5 will focus on the textual description of palliative caregivers’ experiences of compassion fatigue in a hospice setting.
CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter considers the textual description of palliative caregivers’ experiences that was generated from the raw materials in Chapter 4. The study followed a qualitative phenomenological method for data collection and analysis. This chapter also outlines limitations of the study and suggestions for further research.

5.2 AIMS REVISITED

The overall aim of this study was to explore palliative caregivers’ experiences of their physical, psychological, spiritual, emotional and relational dimensions of compassion fatigue in the context of a hospice. The significance of this study stemmed from wanting to understand the phenomenon of compassion fatigue from palliative caregivers’ point of view. An understanding and insight that is provided by palliative caregivers of compassion fatigue when caring for critically ill or near end-of-life patients enabled us to understand the positive and, more especially, the negative aspects of palliative care and the effect of compassion fatigue, with the aim of putting healthy and effective strategies in place that will reinforce resilience in palliative care workers.

5.2.1 The specific aims of the literature study

The participants recruited from Bophelong Hospice included seven (7) palliative caregivers. The participants have a depth of experience in a broad range of patient care environments. The significance of this study stemmed from wanting to understand the
phenomenon of compassion fatigue from palliative caregivers’ point of view within a hospice context. All the participants volunteered to take part in this study and were keen and comfortable to share their stories and experiences as palliative caregivers.

During the interviews, the participants were asked what their experiences are when caring for chronically ill or near end-of-life patients, with the aim of capturing their experiences of compassion fatigue and how it impacts on their overall functioning. All the participants were unfamiliar with the phenomenon of compassion fatigue; however, they were able to describe their experiences clearly and the impact of those experiences on them.

All the participants have been working in a palliative care hospice for more than two years, making them the perfect candidates for understanding compassion fatigue as a phenomenon that may impact the lives and wellbeing of palliative caregivers negatively. During the interviews, the researcher heard participants making comments such as “I enjoy my job” or “I love my job”. Despite the challenges and discomfort that their work presents, the participants expressed some level of job satisfaction and commitment to their work.

The structure of describing the lived experience is derived from the thematic analysis of the participants’ interviews and transcripts. Each participant viewed the experience of caring for terminally ill patients within the framework of her values, social and family dynamics. The participants in this study spoke of their experiences as they reflected on them. Each part of the participants’ experience has shown to affect and inform the whole sum of their experience.
5.2.2 Specific aims of the empirical investigation

The specific aim of this empirical investigation was to reveal a deeper knowledge of compassion fatigue through the palliative caregivers’ experiences. Gaining a better understanding of the extent to which palliative caregivers and other healthcare providers are affected by conditions such as burnout and compassion fatigue is critical for the development of a positive and nurturing working environment.

The findings in this research are similar to those of Yoder (2008) in terms of the theme of caring for critically ill or near end-of-life patients being closely associated with the concept of compassion fatigue. The common triggers for compassion fatigue are identified as a high workload, a lack of support, and ongoing exposure to patients’ pain and suffering (Yoder, 2008).

5.3 CONCLUSION TO THE FINDINGS

The author set out to further understand compassion fatigue as experienced by palliative caregivers. The results of this study revealed a variety of compassion fatigue aspects as experienced by palliative caregivers. The findings of this study were solely supported by the descriptions of the palliative caregivers who participated in this study. Units of meaning and themes for each participant were carefully analysed in order to capture a collective description of the lived experiences of the participants. The data showed a variety of emotional responses that are experienced by the participants and the findings are consistent with the research literature that reported the negative effects of providing care for terminally ill or near end-of-life patients (Coetzee & Klopper, 2010; Day & Anderson, 2011; Yoder, 2008).
There is considerable overlap and indistinction between the components and the effects of compassion fatigue (Coetzee & Klopper, 2010). With that being said, it was evident that all the participants experienced compassion fatigue in varying degrees (Coetzee & Klopper, 2010; Day & Anderson, 2011; Giles, 2011; Yoder, 2008). It was also evident that compassion fatigue is a probable outcome for palliative caregivers who are constantly exposed to individuals who are terminally ill or near end-of-life. The participants in this study expressed various symptoms of compassion fatigue, putting them at high risk of compassion fatigue. This study revealed information on the cumulative effect of compassion fatigue for palliative caregivers.

During the interviews, participants reflected on the numerous details of emotional issues, personal issues, behavioural and physical issues. However, they still have to handle multiple tasks at the same time in order to meet the demands that are placed on them by their professions as palliative caregivers and as mothers and spouses. These have led to the participants going through less desirable experiences that are noticeable. It is not surprising that the participants in this study expressed high levels of stress that cause them to feel loss of control and powerless over their work and home environments.

Some have reported feeling guilty, feeling helpless and in less control resulting from the loss of patients. They felt that they are not doing the best or enough for their patients and put more responsibility on themselves for situations that are beyond their control. This is an emotional component that has led to the participants doubting their capabilities with their caregiving. The participants viewed themselves in relation to others. They are concerned about ensuring that those they care for are well provided for and taken care of, neglecting the fact that they too need to be taken care of. This clarifies the importance of
understanding how vulnerable palliative caregivers can be and the importance of support for them to effectively manage everyday work stress. This may escalate their negative experiences as they may no longer be as motivated as individuals who became caregivers due to having a passion for or an interest in the helping profession. There are participants who felt that they lose interest easily in their work, which may be an indication of not being satisfied in their careers.

It is important to understand the reason behind the caregivers’ motives for their choice of profession. One participant in particular highlighted a lack of options in careers as a reason why she is a palliative caregiver; this makes them even more vulnerable to compassion fatigue. The extent to which palliative caregivers expressed dissatisfaction in their work was evident in this study. Some expressed the need to change careers and even expressed the need to give up altogether. Because of economic reasons, they are compelled to continue working.

Positive elements, such as motivation and coping, are important in ensuring that the participants are able to feel positive about their caregiving experience. There are participants who felt that caring for terminally ill or near end-of-life patients is stressful, but still had the motivation to try to make a difference in their patients’ lives. When losing a patient, the participants felt loss and a sense of hopelessness. However, when they see a patient recover they reported a sense of hope and fulfilment. This has shown that there are positive and negative elements in their experiences as palliative caregivers. It is rather important for palliative caregivers to be aware of their negative reactions to caregiving and to be provided with the skills and support to enhance the positive reactions towards caregiving. With that being said, the participants have acknowledged that they do have
support available to them in the hospice. There might be a need to consider tailor-made support interventions for different palliative care contexts to ensure the effectiveness of such support.

5.4 CONTRIBUTIONS

These unique dimensions will ensure that palliative care service is improved, providing organisations with evidence to develop interventions to maintain optimal working environments and employees’ wellbeing that is prioritised, as it would otherwise negatively affect the caregivers’ nurturing ability. Professional growth and development start with compassion, patience and support (Joinson, 1992).

This study is the first step towards the ultimate design of comprehensive programmes and ongoing interventions. It is important for palliative care training and development to have insight into the experiences of palliative caregivers of compassion fatigue.

There is obviously a need for attention and allocation of resources to the palliative care services in the country, and they are mostly non-governmental organisations (NGOs) or privately owned.

5.5 LIMITATIONS

Phenomenological studies do not focus on the number of participants, but rather on the richness of the collected data. A limitation of this study was the small number of participants who took part in this study. The implication of having a small sample is that the results are not representative of the entire caregiving population. The number of participants in this study may be limited by the number of years of service that caregivers
have in palliative care. The caregivers must have been involved in palliative caregiving for a minimum of two years, which might have resulted in only seven caregivers participating in the research.

The other limitation with regard to the number of participants is that the other hospices from which the researcher intended to access participants were not fully cooperative and some did not even respond to the request to conduct a study in their institution. The researcher believes that more results may have been found if the number of participants were larger and from different hospice contexts.

Another limitation of this study is that the participants might have been influenced by the researcher’s presence, wording of questions and expectations about the participants’ answers.

The participants in the current research were competent in English; however, it is important to acknowledge that English was not their first language. This may have caused difficulties to communicate their emotional experiences adequately and therefore they should have been encouraged or informed of the option to express themselves in the language most comfortable to them. The participants had limited, if not no, knowledge of what compassion fatigue is. The researcher had to ask questions that enabled the participants to express in detail their everyday experiences as caregivers for terminally ill patients.
5.6 SUGGESTIONS FOR FURTHER RESEARCH

The first suggestion is that, given the larger number of research done on compassion fatigue in Canada (Perry et al., 2010; Sabo, 2008; Woods, 2011) and in the United States (Gentry, 2002; Palomino, 2008; Parker, 2009; Robinson, 2005), there is a need for more research in South Africa and Africa as a whole.

The second suggestion for further research is a need to understand the impact of compassion fatigue from a family’s perspective.

Currently little is known about the relationship between work experience, length of experience, years of education or other demographic variables, and how they relate to the prevalence of compassion fatigue (Campbell, 2013). Further research on the impact of demographic variables on the palliative caregivers’ development of compassion fatigue may provide more clarification on the possible causes of compassion fatigue.

Given the lack of knowledge by caregivers of the concept of compassion fatigue, the researcher suggests an investigation into training and education programmes that will equip caregivers with the knowledge of what compassion fatigue is, how it can impact their lives, families and work performance. Signs and symptoms of compassion fatigue and interventions and tools that are in place to reduce the symptoms of compassion fatigue should form part of such training.

5.7 CONCLUSION

Caregiving for the terminally ill patients continues to pose challenges to caregivers’ health, emotional wellbeing and their social and family functioning. The present study was enable
to highlight the difficulties of caring for terminally ill patients from the perspective of the caregivers. The findings revealed that these caregivers are in one way or another negatively affected by their caregiving experiences, therefore making them susceptible to compassion fatigue. Expansion is needed in the area of research to further understand compassion fatigue in different contexts, and ways to educate and support caregivers who may be at risk of developing compassion fatigue.
REFERENCES


APPENDIX 1

Letter of Request for Participation in a Research Study

Date: 25 June 2014

Organisation Name: Bophelong Community Hospice,
Mamelodi

Re: Participation in Exploring Palliative Caregivers Experiences on Compassion Fatigue

My name is Boitumelo Maja and I am writing this letter to introduce you and your staff to a research project that I hope you deem worthy of participation. I am a Masters in Research Psychology student from University of South Africa (UNISA) and I am working on this project alongside my supervisor Gcina Kheswa of the Psychology Department at UNISA.

I request your organisation to grant their palliative caregivers a permission to participate in a research study that will explore palliative caregiver’s experiences on compassion fatigue within the hospice setting in Tshwane district (Gauteng Province). Compassion fatigue is a form of secondary trauma that result from working in a caring profession where we would like to get a better understanding on the palliative caregivers experiences on compassion fatigue.

Your organisations palliative caregiver’s participation in this research study can yield finding that can serve as a new insight that will contribute positively in the development of comprehensive programmes and ongoing interventions for palliative caregivers to ensure a positive and nurturing working environment. I am in the process of identifying palliative
caregivers who would be interested in participating in the research study. The criteria for palliative caregivers will be: a) they need to have been working as palliative caregivers for over three years, b) able to communicate in English and any of the South African languages, and c) they need to be over the age of twenty years of age.

I am thankful for your time and look forward to hearing from you shortly.

Respectfully,

Boitumelo Maja

Contact: 082 8844267/ e-mail: tumizina@gmail.com

Master’s in Research Psychology Student (UNISA)

Date: 19 June 2014
APPENDIX 2

Information letter for the participants and other signed consent form

Dear Potential Participant

I am Miss Boitumelo Kgabo Maja, Registered Research psychology Masters student with the University of South Africa. As part of my studies, I am required to collect information and write a research report. The topic of the research study is Palliative caregivers lived experiences of compassion fatigue in a hospice setting within the Tshwane district.

The purpose of the interview is to understand palliative caregivers experiences and the meaning they have made from their experiences, the stories they tell may add a holistic understanding of Compassion Fatigue as a phenomenon of interest. The knowledge and understanding gained from these interviews could assist the hospice organisations and the policy makers in understanding the impact of palliative care has on the career and the importance of self-development and self-care training for the caregivers as well as understanding the importance of a healthy and supportive working environment in the improvement of service delivery.

You are under no obligation to participate, but I do value your experiences and will appreciate it if you were willing to be interviewed. You may discontinue with the interview at any stage and you may refuse to answer specific questions, without incurring any negative effect whatsoever. The interview will be audio-taped and later transcribed verbatim. Only I, my supervisor and transcriber will have access to the recorded and transcribed interviews. The transcriber will have to sign confidentiality agreement and not
to share the data with anyone also to not keep any copy of the transcript with her or him but hand all the copies back to me for safe keeping. No names will be used or mentioned in any research report, but I will use numbers or letters instead. All palliative caregivers that took part to this study will have access to the research report.

If you are willing to participate in this study, kindly sign this form for record purposes only. You can seal the signed consent form in the envelope provided and place it in the sealed container provided. No names will be attached to your interviews so that no one can link any interview to any specific person.

I have read the information about Miss Boitumelo Kgabo Maja and I agree to be interviewed by her.

.......................................................... ..........................................................
Signature Date

If there are any issues or questions regarding this study please feel free to contact Miss Boitumelo. K. Maja via e-mail at tumizina@gmail.com.
APPENDIX 3

Ethical consent

ETHICAL CLEARANCE OF A RESEARCH PROJECT INVOLVING HUMAN PARTICIPANTS

Project: Exploring palliative caregivers experiences of compassion fatigue in a hospital

Researcher: Boitumelo Maja

Supervisor: Mr GE Kheswa (Psychology Department, Unisa)

The proposal was evaluated for adherence to appropriate standards in respect of ethics as required by the Psychology Department of Unisa. The application was approved by the departmental Ethics Committee on the understanding that certain conditions related to the confidentiality of the information will be met, to the satisfaction of the supervisor. These are noted in an accompanying letter.

Prof P Kruger
Department of Psychology
College of Human Sciences
University of South Africa