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Meunajo Tjiroze Date

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To all those who have taken the often uncertain journey of caring for a loved one with Cancer. Thank you for being a testament to brave love.

“In the flush of love’s light, we dare be brave
And suddenly we see, that love costs all we are
and will ever be
Yet it is only love
which sets us free.”

Maya Angelou

ABSTRACT

The research conducted was an exploratory study. The global aim of the study was to investigate the relationship between distress and the approaches to coping used by informal caregivers of cancer patients within the Namibian context. Adult caregivers (N= 65) visiting the Dr. A. Bernard May Cancer Care Centre as well as the Cancer Association of Namibia's head office completed survey questionnaires. Bivariate correlations were conducted on the data in order to ascertain the unique relationship between the variables. The variables under investigation were; distress, anxiety, depression, caregiver burden, sense of coherence and coping strategies used by caregivers. In relation to global psychological distress a statistically significant level of distress was reported by participants. Caregivers reported experiencing mild levels of anxiety (22.9% positive cases) and high levels of depression(53.8% positive cases). Mild to moderate caregiver burden was reported by 41.5% of participants. The coping strategies used most by caregivers in this study were emotional support and acceptance followed by religion, instrumental support and positive reframing. A significant positive and moderate correlation was found between distress and depression ($r = .36, p < .05$). A significantly strong correlation was found between distress and the use of emotional support ($r = .33, p < .05$). Denial was moderately and significantly associated with distress ($r = .24, p < .05$). Overall the research findings are consistent with previous research as 64.7 % reported significant levels of distress, which when added to the notable level of depression found, may serve as an indication of the psychological strain of this form of caregiving. The inverse relationship found between distress and certain coping strategies may indicate potential buffering effects of certain coping strategies used by cancer caregivers within the Namibian context.

CHAPTER ONE

MOTIVATION, AIMS AND ORIENTATION OF STUDY

1.1 Introduction

This research study aimed at investigating caregiver distress and coping in adult family caregivers of cancer patients. Throughout this research, the broad term family has been used to refer to individuals who are closely bonded socially to the patient. The nature of close relationships varies widely, and some individuals who are considered family may not be next of kin or immediate relatives. Though this may be the case often within the care setting, these individuals frequently assume the role of informal caregiver to the ill person. Since cancer is a possibly terminal illness, a diagnosis involving cancer may be stress-evoking for both patients and caregivers (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2000; Reese, Clarke, Waldron, O'Boyle, Ewings, & MacDonagh, 2005). In addition McCorkle and Pasacreta (2001) assert that family caregivers of cancer patients often become caregivers by proxy, although a proportion of these caregivers might lack caregiving experience and skill. Aneshensel, Pearlin, Mullan, Zarit, and Whitlach (1995) referred to such caregiving as a type of unexpected career. Consequently such caregiving has been associated with high levels of prolonged stress (Cooley & Moriarty, 1997).

Aneshensel et al. (1995), suggest that personal resouces might explain the differential coping strategies and reactions to prolonged stress associated with informal caregiving of ill persons. Research findings emerging from this research study may contribute to the promotion of better-tailored interventions for Namibian family caregivers of cancer patients. The aim is to realistically empower family caregivers of cancer patients to employ actions and decisions benefiting self, patient and family to successfully reduce distress and expand coping.

1.2 Orientation of the study

The research is anchored within the field of psycho-oncology (also known as psycho-social oncology). According to Holland (2002), this field is concerned with the psychological, social, behavioural, and ethical facets of cancer. This particular branch of oncology entails a specialty in cancer care. Holland (2002) further explains that psycho-oncology addresses two key psychological dimensions of cancer; Firstly the psychological responses of patients as well as their informal and formal caregivers at all stages of the disease trajectory. Secondly, the behavioural, psychological and social aspects of cancer that may influence the disease process (Holland, 2002). Psycho-social oncology is a holistic approach to cancer care that addresses a range of needs that may improve quality of life for people affected by cancer, whether patient or patient caregiver (Sherwood et al., 2008; Holland, 2002).

Although statistics regarding cancer in Namibia are limited, there has been growing interest in the field with subsequent research in relation to cancer (Namibian Cancer Registry, 2009; Shino, 2010). The surge in cancer research and epidemiological information gathering may be due to the increased prevalence of cancer in Namibia.

The incidence of all forms of cancer including non-malignant melanoma between the year 2000 to 2005 was 69.4% per 100 000 for males and 67.6% per 100

000 for females (Namibian Cancer Registry, 2009). Koegelenberg (2009) reports a yearly diagnosis of eight hundred (800) to a thousand (1000) cases of cancer in Namibia. However, despite this increase in cancer prevalence, research in the area of psycho-social oncology in Namibia still remains sparse (Shino, 2010). The aforementioned may imply that the knowledge base regarding informal cancer care in Namibia is very little and therefore appropriate psychological support structures for patients and their caregivers may still be within their infancy.

Shifts in health care economics, especially during the end of the twentieth century has lead to more care and recovery of cancer patients occurring at home, therefore having a potentially greater impact on the roles and responsibilities of the family members (Nezu, Nezu, Felgoise, & Zwick, 2003). Optimal care is therefore increasingly hinging on careful planning across settings during treatment (e.g., the transition from being an inpatient at a hospital to being an outpatient in need of home based care) (McCorkle & Pasacreta, 2001). Key components of successful caregiving of patients with cancer is increasingly including; a coordinated team for delivery of health care, an involved and committed family, and the availability of ongoing support and education for the patient and family (Lederberg, 1998). Not only is the delivery of care at risk if care is fragmented, but the demands of the illness may place family caregivers at risk for caregiver burden as well as distress as carers struggle to care for the patient with cancer (McCorkel, & Pasacreta, 2001; van Ryn et al., 2011).

Family caregivers may have numerous out of home responsibilities and possibly experience high levels of distress, which could compromise their caregiving capacity. This could jeopardize their ability to assume a caregiver role towards the patient with cancer (Haley, 2003; Lederberg, 1998). Fortunately, health care professionals are increasingly recognizing the central role of family caregivers in cancer management (Panke, 2002; Schumacher, Stewart, Archbold, Dodd & Dibble, 2000). It is being acknowledged that family caregivers play an essential role in various aspects of care such as; promoting compliance with medical treatment, managing treatment side-effects, performing practical tasks, and providing emotional and social support (Girgis & Lambert, 2009; Kim & Schulz, 2008). Family caregivers often function as proxies for patients in reporting symptoms and psychosocial distress (Sales, 2003). However, studies indicate that family caregivers tend to overestimate the psycho-social distress of patients which may be as a result of their own under-reported burden and distress (Lobchuk & Degner, 2002; Panke, 2002). Factors that may further contribute to caregiver distress may include; the disruption of family roles and routines as well as the possibility that exists that the patient may die. Together with the altered nature of the relationship with the patient due to hospitalization, and changes in peer-group roles, all present powerful potential stressors to the family caregiver (Thastum et al., 2008).

In Africa the burden of caregiving is often left to relatives of cancer patients. Ohaeri, Campbell, Ilesanmi and Omigbodun (1999) assert that there seems to be a tendency to rely greatly on the renowned supports of the African extended family system. For the untrained caregiver, caring for an ill patient may be very demanding. Informal caregivers may be required to develop caregiver skills such as empathy, patience and special communication skills (Panke, 2002; Haley, 2003). Those who offer this informal care to cancer patients have a significant influence on the patients well-being and the relationship between caregiver-burden and patient's psychological morbidity has been acknowledged (Shroder & Schwazer, 2000). The aforementioned statement expounds on the importance of seeking to strengthen the resources of caregivers as it has an implicit impact on the cancer patient (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

Despite the psychological morbidity experienced by caregivers, some family caregivers cope and adjust relatively well (Teschendorf et al., 2006). This adjustment may be attributed to personal coping resources, such as sense of coherence (i.e, generaly better perceived mental health), social support (Chambers, Ryan, & Connor, 2001), appropriate coping strategies (Culver, Arena, Antoni, & Carver, 2002) and optimism (Northouse, Kershaw, Mood, & Schafenacker, 2005), which may serve as buffering effects that promote resillience.

1.3 Problem Statement

Family caregivers play a critical role in caring for patients with cancer and experience a myriad of stressful demands from their care tasks and caregiving experiences, which may be taxing on their emotional and physical resources (McCorkel & Pasacreta, 2001). Caregivers might have to make stressful end-of-life decisions, such as whether to use a hospice care or other palliative care services and in some instances, whether to terminate life support (Haley, 2003). Caregivers are also simultaneously obliged to remain a source of emotional support for the patient (Teschendorf et. al., 2007). Psychological morbidity in caregivers includes aspects such as loss of control, financial strain, role changes, death anxiety, social stigma, and general life uncertainty (Andersen, 2002). Despite the adverse psychological sequel of informal caregiving, there is a lack of research in Namibia regarding informal cancer caregiving.

1.4 Aims and objectives

The global aim of this study is to explore and describe psychological distress and coping strategies of informal caregivers of cancer patients in Namibia.

The more specific objectives of this study are as follows:

- to explore distress experienced by informal caregivers,
- to investigate the relationship between informal caregiver distress and anxiety,
- to examine the relationship between informal caregiver distress and depression,
- to investigate caregiver burden as experienced by informal caregivers,
- to explore the relationship between caregiver burden and distress as experienced by informal caregivers,
- to describe coping strategies employed by informal caregivers,
- to investigate the relationship between caregiver burden and coping strategies of informal caregivers,
- to investigate the relationship between distress and coping strategies used by informal caregivers,
- to investigate the relationship between sense of coherence as a health promoting resource and coping strategies used by caregivers, and
- to examine the relationship between demographic variables and the distress experienced by informal caregivers.

1.5 Significance of the study

Considering the incidence of cancer recorded each year in Namibia as well as the side-effects of cancer treatment, it is expected that a substantial proportion of adults may emerge as informal caregivers of patients with cancer. The social realities are that these informal caregivers might lack specialized caregiving skills; which might predispose them to experiencing financial, social, physical and psychological burden (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). The findings flowing from this research project might strengthen future interventions specifically designed for family caregivers of cancer patients.

1.6 Definition of key concepts

1.6.1 Family caregiver

A caregiver might be a trained professional, a layperson, or a family member or friend involved in the physical, psychological, emotional and/or spiritual caregiving of individuals in need of care (Van Dyk, 2005). Throughout this research, the broad term family has been used to refer to individuals who are socially bonded to the patient with cancer. The nature of close relationships varies widely, and some people who are considered family may not be next of kin or immediate relatives. However, within the care setting, these individuals are frequently caregivers for the ill person. Family caregivers may thus include family members and relatives such as parents, siblings, cousins and other extended family. Family caregiver may also refer to individuals who are not direct relatives such as friends, co-workers, neighbours, and fellow members of religious groups or other organizations. Within this study the terms family caregiver, informal caregiver and caregiver are used interchangeably to refer to the same concept.

1.6.2 Caregiver distress

The term caregiver distress refers to a discomforting psychological state, following lasting or heightened stress that originates from caregiving role demands. Distress is attributed to individual’s appraisal of the accompanying challenges, as well as an appraisal of available coping resources, along with personal responses to those perceived challenges associated with caregiving role demands (Fitzell & Pakenham, 2010). The National Comprehensive Cancer Network (NCCN) has offered a definition of distress which is specific to the oncology context. The NCCN defines distress as “a multifactorial, unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fear to disabling conditions, such as clinical depression, anxiety, panic, isolation, and existential or spiritual crises” (NCCN, 2013, p. DIS 2).

1.6.3 Caregiver coping

Coping refers to utilization of strategies that allow the individual to overcome difficulties and challenges (Carver, Weintraub, & Scheier, 1989). Thus, coping is enhanced by the deliberate or unintended employment of adjustment promoting strategies, in order to meet caregiving demands (Carver & Antoni, 2004). Coping requires that the individual demonstrates observable behaviour aimed at problem solving and dissolution of distress associated with caregiving demands (Mayor, 2006). Caregiver coping is associated with diversification of resources, mutual support and stress management (Kelly, Parker & Gelb, 2002). Caregiver coping is also the behavioural and personal resources employed to adapt to environmental pressures and caregiving demands (Eriksson & Lindström, 2006).

1.7 Overview of chapters

The research is divided into the following chapters:

Chapter Two discusses the psychosocial outcomes of informal caregiving within the broad context of chronic illness. The definition of cancer and its prevalence is presented in terms of the global prevalence of cancer as well as more specifically African and Namibian statistics. The psychosocial outcomes of cancer on the patient and formal caregiver are then examined. This is followed by an investigation guided by findings from previous research, of the novel role assumed by informal caregivers and the psychosocial distress which informal caregivers may experience. Coping resources as well as strategies used by informal caregivers are reviewed and definitions of various concepts relating to distress and coping are offered.

The theoretical perspectives relating to the psychosocial distress and coping of informal caregivers are outlined in the latter half of Chapter Two. Caregiver distress is set within the perspective of caregiver stress, burden and depression. Lazarus and Folkman's stress and coping theory offers a theoretical context for the association between distress and coping. This is further established through a review of coping resources in the form of individual's sense of coherence.

Chapter Three outlines the research methods and procedures, including the research design chosen, selection of participants, data gathering techniques (including a description of the instruments used) and the methods of data analysis.

The results of the data analysis are presented Chapter Four. In Chapter Five, the results of the study are discussed and relevant conclusions are drawn. The limitations of the study and recommendations are also outlined.

CHAPTER TWO

LITERATURE REVIEW: PSYCHOSOCIAL ASPECTS OF CAREGIVING WITHIN THE CONTEXT OF CANCER AND THEORETICAL BACKGROUND

2.1 Introduction

Caregiving of the ill can be a strenuous task which can put at risk carers' physical, psychological and social well-being. Informal caregivers are sometimes called upon to perform conflicting roles. The strain experienced by caregivers can be particularly high when the care recipient has a severe and prolonged illness (Brodaty & Green, 2002; Daly, Douglas, Lipson, & Foley, 2009). Not only is assuming the caregiving role strenuous, but the patients' own negative experiences of the illness often exacerbates the strain felt by informal caregivers (Haley, 2003). Patients with chronic illnesses such as rheumatoid arthritis and cancer, have been found to frequently experience impaired psychological functioning which often occurs in the form of psychological distress (Anderson, Bradley, Young, McDaniel, & Wise, 1985; Castillo, Starkstein, Federo, Price, & Robinson, 1993).

An outline of caregiving of the chronically ill will be offered in order to gain a broader perspective of what literature has found in relation to caregiving of the chronically ill. This will be followed by a definition of cancer as well as a brief discussion of the prevalence of cancer within Namibia. This presentation will serve as a foundation to offer a clearer understanding of this illness and its physical as well as psychosocial outcomes. Focus will then be shifted to both formal and informal cancer caregiving in order to describe the similarities and differences between these two types of caregivers. Closer attention will then be placed on the psychosocial affects of cancer on patients and their informal caregivers. Lastly the psychological burden and distress experienced by informal caregivers as well as the coping mechanisms they use in order to mediate their distress will be explored.

2.2 Chronic illnesses

The World Health Organization (WHO, 2005) defines chronic illnesses as a category of conditions with shared features: including the fact that chronic illnesses take a long period to develop and require methodical approach to treatment over time. Epidemiological findings show that sub-Saharan Africa is the only region of the world in which infectious disease mortality rates are higher than those of chronic illnesses at a rate of 69% (WHO, 2008). de-Graft Aikins et al. (2010) admits that the difference in mortality attribution may result in the miss-perception that chronic illnesses are a less significant contributor to the burden of disease on the continent. In the same vein Unwin et al. (2001) lends support to the critical nature of chronic illness by stating that adults' over-all age-specific mortality rates from chronic illness are higher in younger adult age groups than in most first world countries. The WHO (2008) data reflects that age-specific mortality rates from chronic illnesses are higher in sub-Saharan Africa than in virtually all other regions of the world. Though this may be the case Alwan et al. (2010) argues that many government health agencies respond in an inadequate manner to this issue with regards to lack of chronic disease plans and policies.

A notable proportion of the international burden of chronic diseases is born by the African continent, along with developing countries in Asia and Latin America (WHO, 2008). The WHO (2008) further estimates that over the next decade, the continent is likely to experience the largest increase in mortality rates from cardiovascular disease, cancer, respiratory disease and diabetes mellitus. The report attributes Africa's chronic disease burden to a number of multi-dimensional factors. These factors include, increased life expectancy, changing lifestyle practices, poverty, urbanisation and globalisation (WHO, 2008). Currently, HIV/AIDS is one of the chronic illnesses which places a significant burden on the African continent.

According to the joint United Nations Programme on HIV/AIDS (UNAIDS, 2009), nearly 60 million individuals have contracted HIV since the epidemic began. It is further reported that 25 million people have died of HIV/AIDS-related causes. The African continent has experienced an increase in HIV/AIDS prevalence. Sub-Saharan Africa ranked globally as the most affected region, with an estimated 67% of all individuals living with HIV/AIDS being found in this area (UNAIDS, 2009). Regional statistics of 2008 reflect that sub-Saharan Africa had a recorded 1.9 million new infections. As previously stated the global prevalence of chronic illness is increasing and Africa is bearing most of the brunt of this pandemic. Despite this fact there remains an apparent lack of research with regards to chronic illnesses. A South African study reports that the country has experienced a quadrupled burden of disease (Bradshaw et al., 2003). The aforementioned study asserts that this burden of disease includes pre-transitional illnesses, chronic illnesses and injuries.

2.2.1 Informal caregiving of chronically ill

There has been marked improvement in the provision of health care and advances in treatment. This progress has lead to the increased life span of individuals with chronic illnesses (Nijboer et al., 2000; Ohaeri, Oladele, & Ohaeri, 2001). The prevalence of chronic illness has consequently increased and it has been noted that in the United States nearly half of the population have some form of chronic illness (Gurung, 2010). Consensus is found in literature with regards to chronic illness extending over many years and in some cases an entire lifetime (van Ryn et al., 2010; Girgis, Johnson, & Aoun, 2006). There has thus been a global trend in recent years towards decentralization of health care and more people are opting for home-based care, partly due to the high costs of hospitalization and hospice care (Lim & Zebrack, 2004). The increase in life expectancy of individuals with chronic illness has lead to a consequent rise in the number of individuals providing informal care (Nijboer et al., 1998). This may be because of the fact that informal care is considered as the most practical form of care for chronically ill persons (Mellon, Northouse, & Weiss, 2006).

As stated in the previous chapter, informal caregiving is considered to be a type of unexpected career. As opposed to more conventional careers, caregivers who assume this role do not foresee themselves entering this allegorical career due to the sudden onset of the illness (Kim & Schulz, 2008). Informal caregivers consequently lack a degree of anticipation in relation to their assumption of the carer role. Prior research has found that family caregivers provide the majority of home-based care for individuals with chronic illnesses for prolonged periods (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003; Girgis, Johnson, Aoun, & Currow, 2006). According to the U.S Department of Health and Human Services (2008) an estimated 52 million Americans were reported to be caring for ill or disabled friends and family members. The report further stated that a significant proportion of persons who require long-term care receive it from informal caregivers. The National Alliance for Caregiving (2009) reports that 66% of informal caregivers are women.

The U.S Department of Health and Human Services (2008) also report that in the proportion of female informal caregivers who are employed was similar to that of non-caregiving women in the workforce. Sixty-four percent (64%) of informal caregivers were found to be employed and of that proportion of employed caregivers 65% were reported to have cared for more than one person within the period of reporting. It can be deduced that caregivers are often necessitated to juggle multiple roles, for instance a wife and mother having to assume care for an ailing parent or a doctor having to re-schedule clinical rounds in order to care for a chronically ill spouse. Caregiving of the chronically ill may have far reaching implication on other facets of the caregiver's life (de-Graft Aikins, 2006). Carers may experience strain because of their informal caregiving role (Teschendorf et al., 2006).

The juggling of multiple roles is not the only source of strain as they are also required to administer complicated medical treatments which require prior knowledge regarding their administration (de-Graft Aikins, et al., 2010; Sales, 2003; Kim & Schulz, 2009). The shift from formal to informal care has placed considerable demands on caregivers as well as the informal support structures of patients (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). Individuals who assume the role of an informal caregiver often lack the essential skills required for providing care when assuming their role as caregivers (Han & Haley, 1999). The lack of caregiving skill may prove to be an aggravating factor in relation to the role strain experienced by individual caregivers (Pinquart & Sorensen, 2003; van Ryn et al., 2011). The nature of the care being provided to individuals who are chronically ill may not be static, but rather dynamic in nature. The type of care required by the patient might vary depending on the illness progression as well as possible increased need for assistance with activities of daily living (Raina et al., 2004).

2.3 Definition of cancer

The term cancer is essentially used to describe over 200 different illnesses (Nezu, Nezu, Felgoise, & Zwick, 2003). These various forms of cancer have a common denominator. They are all as a result of the uncontrollable growth of irregular cells and their accumulation. Cancer cells do not adhere to biological rules and as a result they do not go through the usual cell cycle. Instead of following the normal cell cycle cancerous cells divide more rapidly than usual. These cells do not grow in a sequential manner and are unable to mature correctly. The abnormal process of development can lead to the accumulation of cancer cells. This leads to the formation of tumours. If the propagation of cancer cells continues unimpeded, it could spread to surrounding areas and metastasize to form tumours in other parts of the body. The spreading of abnormal cells could hinder body organs as well as systems from their correct functioning and may in some cases lead to death.

Cancer diagnosis was viewed as a death sentence in the past as the survival rate was minimal (Mellon, Northouse, & Weiss, 2006). It has been reported that general cancer mortality has decreased by 16% since 1950 (Nezu, Nezu, Felgoise, & Zwick, 2003). As discussed earlier the impact of cancer diagnosis extends beyond the patient to the broader social context and has a significant effect on those close to the individual with the illness.

2. 4 Prevalence of cancer

2.4.1 International cancer prevalence

Cancer is a major cause of morbidity and mortality across the world. An estimated 24.6 million people were reported as living with cancer, 10.9 million newly diagnosed cases and 6.7 million deaths were attributed to cancer (WHO, 2005). In 2002 it was reported that cancer was the second leading cause of death in industrialized countries and the third major cause of death in developing countries (WHO, 2005). When examining the prevalence of cancer in relation to gender in 2008 there were an estimated 6.6 million men diagnosed with cancer and 6.0 million women (World Cancer Research Fund International, 2008). A further estimation is made that 10% of deaths in developing countries are attributed to cancer, and that cancer incidence is increasing in developing countries (WHO, 2005). In a joint report of the World Health Organization and the International Union Against Cancer (WHO & IUAC, 2005) it was projected that by 2020 there would be 16 million new cancer diagnoses and that of these cases, two-thirds (2/3) would be in newly developed and developing countries.

2.4.2 Cancer prevalence in Africa

There is a lack of epidemiological data on the prevalence of cancer in Sub-Sahara Africa, the validity of estimated incidences rates across the continent are an underestimation. This is as a result of the fact that many cases go unreported. Echimane et al. (2000) however report an estimate from the national cancer registries in West Africa that there is an age standardized incidence rate for all sites ranging from 55.7 - 110.5 per 100 000 population. Comparisons can be drawn between the given estimate and the incidence of 272.6 per 100 000 population in the United States and it can be argued that the discrepancy may be as a result of the skewed estimation of the incidence within Africa. There are several factors which lead to unreported cases of cancer including delays in diagnoses resulting in patients' lives being cut short as well as poor health systems (Epping-Jordan, Galea, Tukuitonga, & Beaglehole, 2005).

2.4.3 Cancer prevalence in Namibia

In Namibia the leading cancers which occur among men include, Kaposi's sarcoma (KS), prostate cancer , lung/ trachea/ bronchus, mouth cancer, Non-Hodgkin lymphoma as well as cancers of the larynx, tongue and colon (Namibian Cancer Registry, 2000-2005). The registry reports that the leading cancers among women include; Breast cancer, cervical cancer, Kaposi's sarcoma, mouth cancer, ovarian cancer, lung/trachea/bronchus, Non-Hodgkin lymphoma, cancer of the uterus, as well as cancer of the colon and tongue.

Kaposi's Sarcoma features among the top three most frequently occurring cancers among both men and woman. The prevalence of this form of cancer may be attributed to the increasing prevalence of HIV among adults aged 15 to 49 (The Namibian Cancer Registry 2000-2005). The occurrence of HIV associated cancers between 2000 and 2005 increased since the previous Namibian Cancer Registry report (1995-1998) with Kaposi's Sarcoma now listed as the most common cancer among males (up from third in males in the previous report) and the third most common in females (KS was not among the top 5 cancers among females in the previous report).

Non-Hodgkin lymphoma is now the fifth and seventh most common cancer amongst males and females respectively in Namibia. The proportion of HIV associated cancers each year has shown a trend of increase with time. The relative frequency of KS increased from 6 to 10% during the period of the previous report. During the period of the 2000- 2005 report, the relative frequency of KS among men was 19.2% and among women was 8.7%. These figures are indicative of the fact that the occurrence of KS is increasing more rapidly among women than men.

2. 5 Psychosocial effects of cancer treatment on patients

The type of cancer which develops in individuals determines the type of treatment which they are likely to undergo. The treatment of cancer has varying approaches which may take the form of surgery, radiation, chemotherapy, immunotherapy and bone marrow transplantation. Any of these approaches can be used as a primary treatment, which is the major intervention for a particular cancer type (Nezu, Nezu, Felgoise, & Zwick, 2003).

Surgery is one of the most common forms of treatment. It involves the removal of the primary tumour as well as tumours which may be metastatic (have spread), residual or recurrent. Surgery is also used to remove the surrounding tissue and affected lymph nodes (Nezu, Nezu, Felgoise, & Zwick, 2003). This treatment approach is sometimes used as a preventative measure. An example of this would be a woman who has her second breast removed in order to ensure that the cancer does not spread to that breast.

Prophylactic treatments such as the use of chemotherapy after surgery are referred to as adjuvant therapy and can be used after the primary treatment has been implemented. This adjuvant therapy forms part of a comprehensive treatment protocol. A woman may, for instance have surgery to remove a tumour in her breast (primary treatment), followed by chemotherapy, radiotherapy or systemic therapy (adjuvant therapy). Adjuvant therapy eliminates those cancer cells not possible to remove during surgery (Nezu, Nezu, Felgoise, & Zwick, 2003). Neo-adjuvant therapy occurs prior to the primary treatment in order to control known or potential sites of metastasis . Prophylactic treatment is targeted to a site where a high risk for cancer development exists. For instance, cancerous cells of the lung have a high likelihood for spreading to the brain, preventive radiotherapy can be used to prevent such metastasis.

The improved survival rates among cancer patients has been argued to serve as a positive indicator of the advancement in cancer treatment and care (Nezu, Nezu, Felgoise, & Zwick, 2003). Nezu, Nezu, Felgoise, and Zwick (2003) further distinguish the current state of cancer care to that of the early part of the twentieth century, where few cancer patients were expected to survive the illness. In the 1930’s however, the survival rate was established as being 1 in 4 cancer patients. The five year survival rate is widely considered as a significant indicator of survival rate and Nijboer et al. (1998) estimated that nearly half of all newly diagnosed cancer patients would survive beyond five years. Nezu, Nezu, Felgoise, and Zwick (2003) revised this statistic, to approximately 4 out of 10 cancer patients who were expected to surpass the five year milestone. The overall survival rate has improved in the past 60 years and the survival rate for all cancer types is 59%.

Various researchers have focused on the diverse physical symptoms of cancer such as weight loss, ulceration of cancer site, swelling, bleeding and impaired sexual functioning (Chachaj et al., 2009; Schwartz & Plawecki, 2002). Cancer patients often endure varying levels of pain either as a result of the illness itself or the accompanying treatment. Additionally, cancer pain varies in prevalence depending on the stage and site of the illness (Nuhu, Odejide, Adebayo, & Yusuf, 2009). Thomason et al. (1998) asserts that approximately one in every three cancer patients receiving treatment for their metastatic illness have experienced pain.

Though there have been advances in palliative treatment, the psychological implications of the pain experienced by cancer patients cannot be overlooked. In the same vain Kurtz, Kurtz, Stommel, Given, and Given (2001) confirm that cancer pain is associated with the development and intensification of psychological distress. In their study Ciaramella and Poli (2001) found that 49% of cancer patients met the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders (DSM III-R) criteria for depression. In reviewing literature, it is apparent that the presence of pain and other physical sequelae also increase the risk of suicide in cancer patients as well as heightened incidence of depression and anxiety (Laird, Boyd, Colvin, & Fallon, 2009; Rivers et al., 2011; Thomason et al., 1998).

2.6 Psychosocial effects of cancer on patients

There is consensus in literature that cancer patients develop clinically significant symptoms of anxiety disorder, post-traumatic stress disorder and depression (Chachaj et al., 2009; Hack & Degner, 2004). A study carried out by Sukegawa et al. (2008) found that adjustment disorder accounted for 33.3 % of the psychiatric outcomes among cancer patients who were diagnosed with ovarian cancer. Some cancer patients exhibit various psychological responses to their illness such as fear, sadness, feelings of discouragement and grief (Horlick-Jones, 2011). These responses are mood states, which do not fall within the range of DSM-IV or (International Classification of Diseases) ICD-10 classifications, but have an impact on the psychosocial well-being of cancer patients.

Grass, Holland, Johansen, Koch, and Fawzy (2005) assert that literature over the past two decades has found that an estimated 30% to 40% of cancer patients report significant psychological morbidity. African prevalence rates for both anxiety and depression among cancer patients range from 14% to 45% is consistent with global prevalence rates (Asuzu, Campbell, & Asuzu, 2008; Boermeester & Berard, 1998; Berard, Boermeester, & Viljoen, 1998; Shino, 2010). These affective outcomes of cancer may be due to the wide range of stressors, which may lead to significantly compromised psychological well-being. Viewed from a broad perspective these stressors may include treatment and illness related stressors as discussed previously. Ballenger et al. (2001) specifically attributes the stressors experienced by cancer patients to a wide range of causal factors including; the incapacitating effects of chemotherapy and other cancer treatments, chronic physical pain as well as metabolic and endocrine modifiers. The preceding factors highlighted by Ballenger et al. (2001) are predominantly physiological in nature and it may thus be argued that this shows the connection between the mind and the body. It has been shown that the type of cancer which individuals have may also influence their experience of negative psychological outcomes.

Massie (2004) outlines research findings related to cancer types which are significantly associated with depression. The author states that prevalence rates of depression ranging from 22% to 57% among individuals with oropharyngeal cancer, 33% to 50% for individuals with pancreatic cancer, 1.5% to 46% for breast cancer patients and 11% to 44% for individuals with lung cancer. With regards to coping with stressors, Nezu, Nezu, Felgoise, and Zwick (2003) argues that those individuals who have not coped well with major negative life events in the past, may find that cancer and its treatment significantly increases the stressful nature of fairly routine daily tasks.

The experience of having cancer may have psychological as well as social and/or spiritual implications. According to Vachon (2006) these implications are of such a nature that individuals' ability to cope with the illness, its physical symptoms as well as treatment which may become compromised. The relevance and significance of psychological outcomes is further underscored by Vahdaninia, Omidvari, and Montazeri (2010) who assert that depression and anxiety are related to higher mortality rates amongst cancer patients. The social implications of cancer include interpersonal challenges faced by cancer patients and their loved ones. An area that has received some research interest is that of sexual functioning and cancer.

Lastly, as eluded to earlier, due to the rising occurrence of HIV/AIDS related cancers as well as the way in which chronic illnesses are perceived within the African context results in cancer patients having to deal with various forms of stigma. According to de-Graft Aikins et al. (2010) stigma is a significant psychological stressor. Stigma has been reported to lead to discrimination and ostracism of people with chronic illnesses including cancer. Holland (2002) establishes the apparent stigma which has long been associated with cancer and states that the advent of enquiry into the psychological implications of cancer has since aided in addressing the issue of stigmatization within cancer.

When considering stigmatization within the African context it has been noted through several research studies, that chronic physical illnesses such as AIDS, diabetes, cancer and epilepsy as well as mental illnesses like schizophrenia and psychosis are stigmatised (Allotey & Reidpath, 2007; Awah, Unwin, & Phillimore, 2008; de-Graft Aikins, 2006). Goffman (1963) is the earliest theorist to conceptualize courtesy stigma which is defined as other's change in perceptions due to their affiliation with the stigmatized person (Werner & Heinik, 2008).

Courtesy stigma is conceptualized as stigma which is not only restricted to individuals with the illness, but also affects people who are affiliated with the patient (Angermeyer, Schulze, & Dietrich, 2003). This form of stigma hence contributes to the discrimination of caregivers and significant others of the chronically ill. Perceived stigma may be associated to self imposed socially restricted lives for both patients and their caregivers (Wight, Beals, Miller-Martinez, Murphy, & Aneshensel, 2007). Werner and Heinik (2008) asserts that courtesy stigma could have several negative outcomes including; anger, distrust, inability to coping and increased subjective burden. The phenomena of stigma within cancer, though not within the scope of this study, can be a significant outcome of the psychosocial affect of cancer on patients. It may also be a contributor to the delay in the seeking of medical treatment (Shino, 2010).

2.7 Psychosocial effects of formal caregiving of cancer patients

Cancer patients have significant contact with trained professional caregivers who are paid to offer care within a broad range of settings in oncology health care. These formal caregivers include oncologists, general practitioners and nursing staff, at different health care institutions. The prolonged and consistent interaction between cancer patients and medical staff may be due to the nature of cancer diagnosis and the extensive treatment and follow-up visits to health care facilities throughout the illness trajectory (Williamson, 2008). Formal caregivers in oncology settings have reported adverse mental health outcomes such as burnout attributed to working with patients experiencing a great deal of suffering as well as being exposed to the deaths of long-term patients (Dorz, Novara, Sica, & Sanavio, 2003).

Formal caregiving within health care not only requires the knowledge necessary to deal with complex medical problems, but an empathic approach towards care recipients is also critical. Health professionals working within the oncology setting in particular are thus required to have added skills sets to deal with the emotional outcomes of cancer patients (Beckstrand, Moore, Callister, & Bond, 2009). The afore-referenced authors further argue that health care professionals are required to oversee various quality of life matters relating to patients and their informal caregivers. Much of the literature exploring the various psychological outcomes of formal caregivers within the field of oncology has been conducted among oncology nurses (Dorz, Novara, Sica, & Sanavio, 2003; Mårtensson, Carlsson, & Lampic, 2010). It may be argued that this focus on oncology nurses may be due to their frequent and prolonged interactions with cancer patients compared to the level of interaction oncology doctors, social workers and psychologists may have. Williams (2001) suggests that there has been a shift in nursing from professional detachment to an approach which places emphasis on fostering an appropriate relationship with the patient.

Medland, Howard-Ruben and Whitaker (2004) make the assertion that oncology nurses are vulnerable to professional burnout which may manifest itself in distress, emotional exhaustion, loss of personal accomplishment as well as depersonalization. It could thus be argued that the over-all psychological well-being of formal caregivers can thus be impacted by their caregiving role. A tension may also arise between health care workers role and the duty they may feel they have towards the patient in their care. According to Lazzarin, Biondi and Di Mauro (2012) formal caregivers sometimes experience moral distress, which is conflict between what may be an ethically appropriate course of action and institutional factors which serve as obstacles. Moral distress can be experienced by oncology nurses who have built a relationship with the patients and their loved ones and may thus have insight into their preferences for care (Medland, Howard-Ruben, & Whitaker, 2004). Hence when nurses are requested by physicians to initiate care which is not in line with previously expressed preferences for care, the nurses may experience an apparent conflict which results in moral distress.

Whilst formal caregivers are required to attend to ill patients they are in some instances simultaneously dealing with their own fear of illness and dying. It has been noted that in the case of oncology nurses they may sometimes experience grief related to patients and nurses emotional experiences hence go unaddressed (Medland, Howard-Ruben, & Whitaker, 2004). This may have an impact on the coping of these health care workers. It may be argued that the experience of informal caregivers who have had no prior exposure to caring for cancer patients may find it equally if not more challenging to deal with their novel role.

2.8 Informal caregiving within the context of cancer

Informal caregivers as outlined in Chapter One, are lay caregivers who provide care to ill individual with whom the carer has a personal relationship with. The pillar of health care for the cancer patients is embodied by access to help with regards to activities of daily living such as eating, adherence to medication and treatment, social involvement, leaving the home to do errands or attending follow ups with the doctor. All this assistance is provided to patients through informal caregivers (Teschendorf et al., 2006). In many cases informal caregivers can serve as accurate historians, first-hand observers of the patient's reactions to medications and treatments, and clarifiers of patient communication with medical personnel at health care facilities (Cifu et al., 2006; Girgis, Johnson, Aoun, & Currow, 2006). Informal caregivers, thus help the medical team obtain accurate and reliable information as well as ensuring the appropriateness of the home environment for the patient.

In accordance with the above discussion, supporting the functioning of caregivers is pivotal to the successful medical management and the patients' return to the community. In a study on home-based care in Botswana, Moalosi et al. (2003) report that home-based care resulted in a reduction of the cost per patient treated by 44% overall compared to hospital-based treatment. The cost-effectiveness of the aforementioned health care trend for both hospitals and consumers is dwarfed by the increased financial, physical and emotional responsibility, which rests on the shoulders of the family caregiver of the ill patient (Rees, Boyle, & MacDonagh, 2001).

The treatment side effects on patients may have implications on the informal caregiver. Fatigue is argued as being one of the most frequently occurring side effect of cancer treatment (Berndt et al., 2005). This side effect has been found to affect an estimated 76% of cancer patients following chemotherapy treatment (Curt et al. 2000). Patients who experience such treatment related fatigue often report it as being severe and may limit the individuals activities of daily living. In the study carried out by Curt et al., (2000) ninety-one percent of the respondents who had reported experiencing fatigue stated that it had an impact on their life in general and 88% reported that fatigue had impeded on their daily routine. As a consequence of severe fatigue as well as the pain which often accompanies treatment, patients are often unable to perform certain tasks, which the caregiver has to assist them with, these include the previously mentioned ADLs (Activities of Daily Living) (Schwartz & Plawecki, 2002). The apparent functional dependence of the care recipient on the caregiver may be accompanied by an emotional dependence as a result of the co-occurring negative psychological outcomes of the illness (e.g. depression, anxiety and distress). Haley (2003) asserts that caregivers provide emotional support to the patient with cancer, whilst meeting the instrumental needs of the patient.

The interpersonal relationship between the patient and the caregiver may be affected differentially depending on the nature of the quality of life (QOL) dimensions affected by the diagnosis and treatment of the illness. An example may be that of the impact of cancer treatment on sexual functioning of cancer patients (Davison, So, & Goldenberg, 2007). Sanders, Pedro, Bantum, and Galbraith (2006) asserts that an estimated 33 – 98% of men who have had prostate cancer report reduced quality of life attributed to sexual dysfunction following treatment. Rivers et al., (2010) argues that patients may experience decreased self-esteem, a sense of inadequacy as well as increased self-consciousness relating to sexual performance which is accompanied by stress, anxiety, depression and inadequate coping. Research focused on partners of cancer patients have found that the negative psychological outcomes experienced by patients are positively correlated with deleterious outcomes in the partner (Kim et al. 2008; Soloway, Soloway, Kim, & Kava, 2005).

As mentioned previously, informal caregivers may assume the role of providing emotional support for the patients, whilst simultaneously assuming responsibility for the practical care of the ill individual. It could thus be asserted that, whether treatment effects are short-term or long-term, physical or emotional by it’s very nature cancer is an illness which often requires loved ones of the patient to occupy the carer role in conjunction with other roles.

It is generally accepted that individuals usually occupy multiple roles in life, such as the assumption of family roles as well as occupational roles. Becoming a caregiver introduces an additional role which often results in the re-evaluation of priorities as well as the redirection of energy. Kim and Schulz (2008) argue that the informal caregiving role could be considered as being comparable to being employed full-time. Stress usually emanates from both the provision of care, as well as other areas of life. When discussing caregiver stress the focus could be placed entirely on stress which is directly associated with the provision of care. Aneshensel (2005) however suggests that recognition be given to stress occurring in a broader social context. This would aid in obtaining a more comprehensive understanding of the broader implications of caregiving.

The management of multiple roles, including vocational and household responsibilities can be an arduous part of informal caregiving and may contribute to caregiver’s experience of distress (Kim & Schulz, 2008). In addition to the multiple roles, caregiver role overload may originate from physical, psychological, emotional, social and financial strains associated with providing care for a chronically ill family member (Pinquart & Sörensen, 2005). This role strain may in some cases be compounded by the stigma associated with chronic illnesses (e.g. HIV/AIDS, diabetes, cancer) within the African context.

2.8.1 Psychosocial effects of cancer on informal caregivers

In a longitudinal study carried out by Rees et al. (2005) it was reported that partners experience significantly higher cancer-related distress than cancer patients in relation to general cancer distress. The authors further assert that their findings are consistent with prior studies which report higher occurrence of psychological morbidity amongst partners of prostate cancer patients as compared to that of the patients themselves (Rees et al., 2005). The consistency of this particular finding in relation to other conditions implicitly suggests a genuine phenomenon. Separate research conducted amongst women with breast cancer found that these women often describe negative consequences of the illness on themselves and their immediate family members (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997).

Partner research has served to broaden the general understanding concerning the psychosocial effects that diagnosis and treatment has on those connected to the patient socially. Research studies have found that partners of cancer patients experience emotional distress and psychological morbidity as a consequence of their caregiving roles (Pitceathly & Maguire, 2003; Bergelt, Koch, & Petersen, 2008). Pitceathly and Maguire (2003) report that the incidence of anxiety is sometimes higher among family caregivers supporting breast cancer patients than the patients themselves. Boyer et al. (2002) found that 13% of daughters of women with breast cancer exhibited a symptom profile consistent with Post Traumatic Stress Disorder (PTSD), and 72% met the diagnostic criteria for at least two of the three PTSD symptom clusters (i.e. re-experiencing symptoms, avoidance, and arousal). Particularly noteworthy is the fact that Boyer et al. (2002) reported that mothers with PTSD symptoms were more likely to have daughters who experienced PTSD, suggesting a shared experience of psychological morbidity.

2.8.2 Burden of cancer caregiving

Family and friends of individuals with cancer, who assume the role of informal carer, are often unprepared for their role as discussed previously. Informal caregivers thus experience elevated emotional distress because of the burden of their caregiving (Lowery et al., 2000). Caregiver burden is essentially the tension or strain borne by an individual who cares for an ill family member or other significant person in their lives. Caregiver burden is marked by the extent to which the informal caregiving situation is no longer a feasible or healthy option for either the caregiver or the ill individual (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Informal caregiver burden has not been explored much within the context of informal caregiving of cancer patients (Daly, Douglas, Lipson, & Foley, 2009). This is despite the fact that the World Health Organization took action in 1990 by recognizing the adverse consequences of informal caregiving (World Health Organization and International Union Against Cancer, 2005). This recognition took the form of setting the needs of family caregivers as one of the main objectives of palliative care.

The essential needs of caregivers can be established more effectively when an investigation is made of the areas of caregiving which are experienced to be most burdensome to these individuals (Bergelt, Koch, & Petersen, 2008). Such investigation is further important because informal caregivers may experience burden, which can have an adverse effect on the caregivers' physical as well as their psychological well-being. Studies have shown that there is a significant correlation between caregivers' psychological needs, carers' perceived burden and patients' well-being (de-Graft Aikins et al., 2010).

Cancer in particular is a chronic illness whose management places demands on the time, social, emotional resources and physical capabilities of caregivers (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Increasing dependence on family and significant others for medical care and self-care can result in emotional conflict. This dependence may also place strain on marital, intimate relationships as well as result in a perceived lack of support (Girgis, Johnson, Aoun, & Currow, 2006). This is particularly poignant within contexts where resources are limited and financial strain may be experienced by informal carers as a particularly salient type of burden (de-Graft Aikins, 2006). The author asserts that this burden can cause emotional conflict and breakdown in marital and intimate relationships, as well as family abandonment.

Cancer has been argued to impact the entire family system, though it may impact specific members of the system differentially due to the nature of their relationship with the care recipient (Pitceathly & Maguire, 2003). The type of relationship between the caregiver and cancer patient may hence have an impact the level of personal, total burden as well as adaptation to caregiving burden. Lowenstein and Gilbar (2000) found that cancer patients’ spouses reported experiencing more perceived burden than children of cancer patients and even patients themselves.

The various forms of strain placed on informal caregivers result in increased levels of caregiving burden. When carers begin to experience high levels of burden, there is an increased likelihood that they would divert care to formal caregivers and institutionalization may become a viable option for such carers (Arai, Sugiura, Washio, Miura, & Kudo, 2001; Miller & McFall, 1991). One of the more specific aims of the research study is to investigate caregiver burden, as it will aid in broadening the understanding of the distress experienced by caregivers. The burden experienced by carers can be exacerbated or mitigated by several factors relating to burden. They include the characteristics of the caregiver as well as the care recipient, social-economic and cultural contexts (Raina et al., 2004).

2.8.3 Distress of informal caregivers within the context of cancer

Aneshansel (2005) defines stress in the context of caregiving as the problematic conditions and difficult circumstances experienced by caregivers. Caregivers experience situations as stressful when they perceive the demands and obstacles placed on them as being of such a nature that they cannot handle nor adapt to them (Siglen, Bjorvatn, Engebretsen, Berglund, & Natvig, 2007). The authors argue that demands placed on the caregivers by the patient’s illness may be of such a nature that they are in direct conflict with their perceived ability to deal with those demands. Stress can also originate from the caregivers experience of the demands which hamper their pursuit of other goals (Teschendorf et al., 2006).

Stress has been argued to be as a result of the discrepancy between the demands of the stressor and the personal resources required to meet this demand (Greenberg, 2011). This discrepancy may serve to explain why some individuals seem less affected by stress, while others experience more detrimental health outcomes (Sapolsky, 2004). Despite the existence of stress there are also several moderators which have an impact on the manner in which stress is experienced by caregivers. These moderators include mastery/self-efficacy, which determine how people are affected differently by the same stressors and may help to sustain the caregiver and lessen the effect of the stressors (Raina et al., 2004).

2.8.4 Coping of informal caregivers within the context of cancer

For each informal caregiver there may exist a number of psychosocial mechanisms that regulate the impact of stress on health and well-being. Teschendorf et al. (2006), identify factors such as the characteristics of the caregiver, the recipient of care, their shared history and common social, economic and cultural contexts. These factors all relate to caregiving and combine to create an infinite variety of circumstances from which stress and stress outcomes (e.g. deteriorating self-concept, decline in emotional well-being) in caregivers are created (Teschendorf et al., 2006). The novel carer role which has been noted previously may require some reshuffling of priorities as well as the utilization of different coping strategies, which mediate stress and increase well-being.

Coping resources are relatively stable characteristics of a person's internal (e.g. disposition) and external (e.g. social support) environments, and refer to what is available to individuals when they develop their coping strategies (Larsen & Lubkin, 2009). Greenberg (2011) asserts that specific psychological resources (e.g., personality characteristics) may influence caregiver outcomes. Kabit-Zinn (2005) argues that personality characteristics such as mastery, neuroticism and self-efficacy seem to be associated both theoretically and empirically, to health outcomes such as depression and anxiety, especially during stressful situations.

In a study carried out by Nijboer, Tempelaar, Triemstra, van den Bos and Sanderman (2000). It was reported that with respect to caregiver's depression and personality characteristics, three significant moderating effects of mastery were observed. Caregivers with a high mastery for whom the patients reported a high initial score on depression showed a lower level of depression over time; in particular, those caregivers with a high mastery who derived the most self-esteem from caregiving reported the lowest levels of depression. In addition, caregivers with a high mastery who perceived little disruption in their daily schedule reported the lowest levels of depression over time (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2000). Moderating effects were observed to play a role within the caregiving process, especially with regard to positive aspects of social support and mastery.

Sense of Coherence (SOC) is a particularly relevant construct when looking at personal resources of caregivers which aid in their coping. It is based on the concept of salutogenesis (Antonovsky, 1993) which has a particular focus on explaining the reasons why human beings stay well despite the presence of adverse circumstances. Sense of Coherence is a salutogenic model which seeks to explain individuals' perception of stressors in their lives. Antonovsky categorized this model into three components namely; comprehensibility, manageability and meaningfulness.

According to the model those with a strong Sense of Coherence may tend to view stimuli experienced as unsurprising and explainable. Individuals with this orientation perceive themselves as having the resources available to meet the demands placed on them by a particular event (Antonovsky, 1993). Such individuals also have the understanding that the demands which they are faced with, are challenges that are worth investing their resources in as well as engaging with the particular event (Eriksson & Lindström, 2006). The proficient management of stressors by individuals with a strong Sense of Coherence result in maintenance and improvement of their psychosocial well-being (Holmberg, Thelin, & Stiernström, 2004).

SOC is strongly and negatively associated with anxiety, anger, burnout, demoralization, hostility, hopelessness, depression, perceived stressors, and post-traumatic stress disorder (Eriksson & Lindström, 2005). Geyer (1997) reported that Sense of Coherence and depression were closely correlated and that there was a negative association between those two variables.

2.9 Theoretical Framework

One of the major areas of psycho-oncology research, as discussed previously, is the psychosocial effects of cancer and its treatment on patients as well as their families. There has been budding interest in the psychosocial effects of cancer on the informal caregivers of cancer patients in recent years (Cameron, Franche, Cheung, & Stewart, 2002; Hagedoorn et al., 2000). Theoretical perspectives have emerged to guide caregiver research, particularly in relation to appraisal as well as outcomes of distress and coping strategies used by informal caregivers. This chapter begins with a brief description of a concept which serves as an introduction to the perspectives which underlie psychosocial distress, by looking at the way in which emotional states can be transferred from person to person. This helps to gain an understanding of the implications of inter-personal interaction on individual's mental health.

As this research investigates the distress experienced by caregivers, several theoretical perspectives have been used which have served as conceptual backgrounds in previous informal caregiver research. They offered a theoretical grounding for the current research. The theories include Pearlin's model of caregiver stress and the six-element model of burden and depression which both focus on aspects of caregiver distress. Coping is reviewed by offering a description of the various aspects of Lazarus and Folkman's stress and coping theory as well as Antonovsky's sense of coherence theory.

2.9.1 Emotional contagion theory

Schacter (1959) theorized that novel threats generate stimulus that results in individuals associating with others. This association enables individuals to establish the nature and appropriateness of their personal reaction in relation to perceived threat. Schacter (1959) further asserts that through the course of this social association, individuals often construct a common social reality. This shared social reality also includes a phenomenon known as emotional contagion, which occurs when emotional states appear to be transferred from one person to another.

Theoretical explanations of emotional contagion assert that people will often “absorb” the emotional states of those around them (Bookwala & Schulz, 1996; Joiner & Katz, 1999). This occurs through unconscious interactional processes. These processes involve imitation and matching of social behaviors (Hatfield, Cacioppo, & Rapson, 1992). Study evidence shows that individual’s anxiety level can be influenced by that of their interactional partner, even when the partner is not facing the same threat (Gump & Kulik, 1997). Several authors have looked at the question of ownership of a particular stressor between two interactional partners (Berg, Meegan, & Deviney, 1998; Bodenmann, 1997; Lyons, Mickelson, Sullivan, & Coyne, 1998). Berg and Upchurch (2007) suggests that patients may initially evaluate the illness as their own. However frequent talks between the ill individual and the informal caregiver regarding stressors may lead to the perception of stressors being shared between the pair. This may be linked to a shift toward a more shared view of illness ownership and a more congruent view of what the illness entails.

Cancer patients and those individuals within their immediate social network are faced with a threat, which for most is experienced as being novel as well as psychologically taxing (Baider & De-Nour, 1999; Grunfeld, Coyle, & Whelan, 2004).

This theoretical perspective is in line with research, which has found that intimate partners are especially susceptible to the emotional state of their ill loved one (Brown & Brown, 2006). The anxiety of one member of this interactional partnership, could be shared by the other member of the social pair, particularly within the context of the caregiver and care-recipient relationship (Hatfield, Cacioppo, & Rapson, 1994). This shared feeling could be because individuals in a close relationship are receptive to experiencing their loved ones emotions due to the fact that they are invested in each others over-all well-being.

Brown and Brown (2006) suggest that this receptiveness is also due to the likelihood that caregivers are attuned to their loved ones emotional states and symptoms. Schulz et al. (2007) asserts that an individual may generally experience similar emotions as the ill loved one, but that there may be exceptions to this and in some instances incongruence may occur. For instance a caregiver may respond emotionally in a certain way (e.g. anxious, fearful, sad) to the pain of the loved one, but their expression may be one of anger. Nijboer et al. (1998) asserts that females and partners of ill individuals are generally more prone to experiencing negative psychosocial outcomes. The vulnerability of partners may be because they provide the most extensive care in terms of their personal investment of resources and time (Horowitz, 1985; Weitzner, Haley & Chen, 2000). Pearlin's model states that the first principle domain, referred to as the background and context of stress, includes characteristics of the caregiver such as socioeconomic status, gender and caregiving history.

2.9.2 Pearlin's model of caregiver stress

The conceptual model of caregiver stress developed by Pearlin, Mullan, Semple, and Skaff, (1990) is a widely used theory within social research and provides an explanation of the process which underlies caregiver distress (Gideon, 2007). Pearlin's theoretical perspective suggests that primary stressors, such as cognitive decline and behavioural disturbances of the care-recipient, generate circumstances under which emotional distress may occur. However, the degree to which caregivers' subjectively experience this distress depends on their evaluation of the situation and the resources they have to aid in managing the stressors associated with caregiving. More specifically, this model classifies the stress process into five principle domains namely, background and context, primary stressors, secondary strains (i.e. role strain and intra-psychic strain), mediators, and outcomes (see Figure 1.1).

Pearlin, Mullan, Semple and Skaff's (1990) model states that the first principle domain, referred to as the background and context of stress, includes characteristics of the caregiver such as socio-economic status, gender and caregiving history. Primary stressors in this model are considered to be recipient characteristics, such as cognitive functioning, challenging behaviours, and level of functional reliance. Pearlin et al. (1990) further asserts that mediators of the stress process can be interpersonal (i.e., social support) or intrapersonal (i.e., caregiver coping strategies) in nature. Finally, outcome variables incorporated in this model consist of cognitive, emotional, physiological and social challenges. The principle domains of the Pearlin et al. (1990) model are based on the requirements and demands of the patient and the caregiving required to satisfy them or in the restructured relationship between caregiver and patient. This model also includes two secondary strains, namely role strain and intra-psychic strain, into the explanation of the stress process. The concept of role strain includes family conflict, clash between job and caregiving roles, economic problems, and restriction of social life. Intra-psychic strains on the other hand include feelings of low self-esteem, reduced mastery and competence, and role captivity. Primary stressors, secondary strains, mediators and outcomes are intricate, interconnected variables in Pearlin's overall model (see in Figure 1.1).

Figure 1.1 Pearlin et al. (1990) Conceptual Model of Caregiver Stress

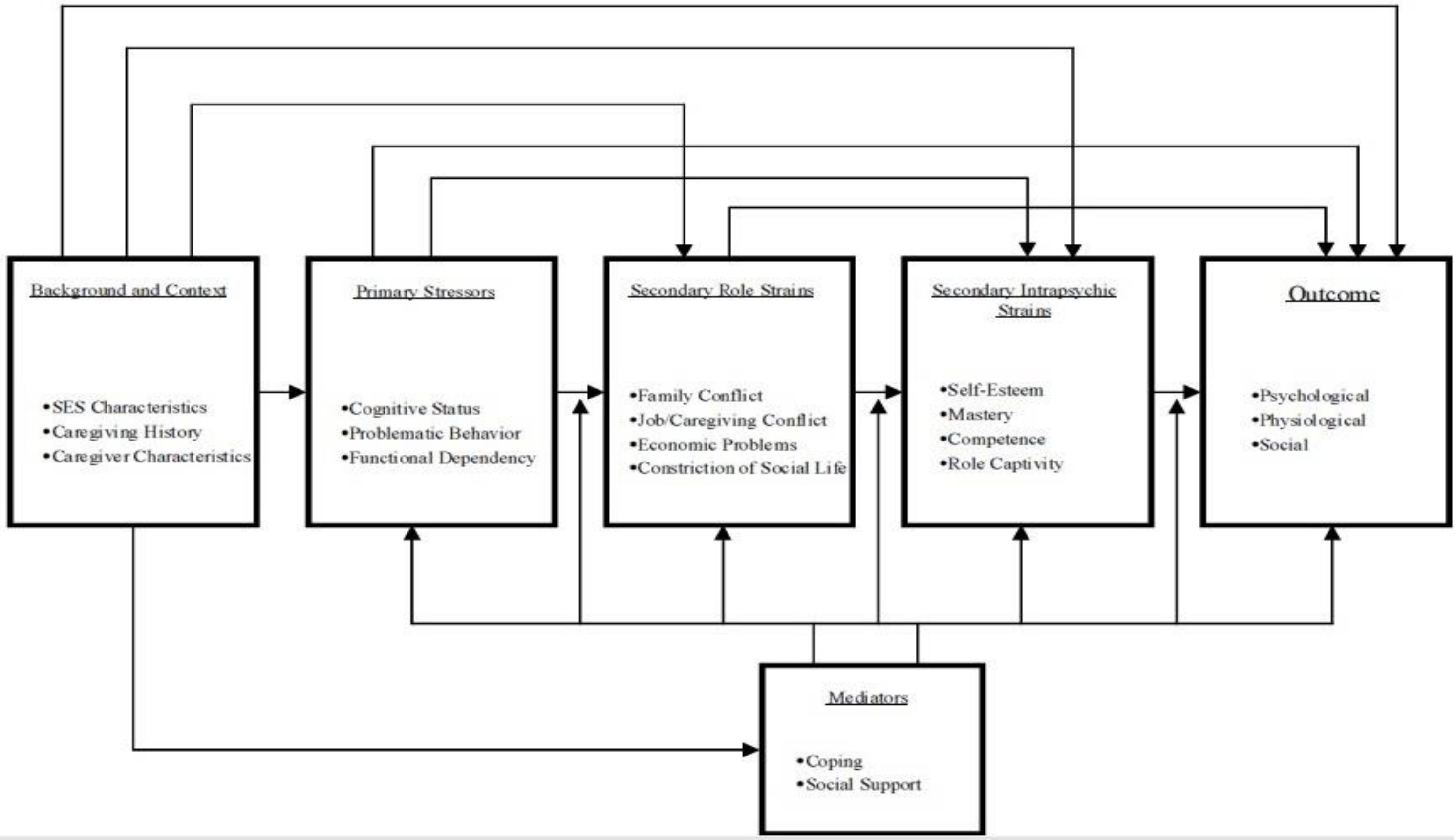


Figure 1.1 Model of caregiver stress (on the basis of Pearlin et al., 1990). Adapted from "Social environments of dementia caregivers : Relationships between social support , negative social interactions and caregiver emotional distress" by C. Gideon, 2007. Doctoral dissertation, Case Western Reserve University.

According to Pearlin et al. (1990), background and context incorporates practically everything of interest concerning caregiving. As can be seen from Figure 1.1, the background and context variables are associated with psychosocial as well as health outcomes, secondary intra-psychic strains, secondary role strains, and coping and social mediators. Figure 1.1 further shows that background and context variables are second only to the mediator variables in terms of its broad interaction with other variables. Its outcomes are potentially influenced by key characteristics of the caregiver. Consequently, researchers have investigated caregiver variables such as age, gender, personality, ethnicity, education level, income and relationship to the care recipient in relation to levels of caregiver psychosocial distress (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994; Torti, Gwyther, Reed, Friedman, & Shulman, 2004).

A number of correlations between these variables and caregiver burden have been identified with relative consistency (Nijboer et al., 1998). An example includes, studies which have found that younger caregivers experience greater mental health symptoms, such as more severe depression, as a result of their caregiving role when compared to caregivers who are older (Polen & Green, 2001; Schneider, Murray, Banerjee, & Mann, 1999). Similarly, female caregivers seem to experience greater subjective burden, or emotional distress, than men (Adams, Aranda, Kemp, & Takagi, 2002; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002).

Research has found that younger caregivers and female caregivers may be more vulnerable to distress due to conflicting demands from multiple roles, such as career, social life and child-rearing (Reid & Hardy, 1999). Caregiver personality characteristics (e.g., lifelong or long-standing inter- and intra-personal tendencies), though not part of the focus of this research study, have also been linked to increased levels of stress (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998). In particular, caregiver neuroticism has been found to play a significant role in the degree of emotional distress experienced by informal caregivers of dementia and cancer patients (Butt, Strauss, Smyth, & Rose-Rego, 2002; Gallant & Connell, 2003; Vedhara, Shanks, Wilcock, & Lightman, 2001). Neuroticism seems to predispose individuals to interpret and react to stress in a maladaptive manner (Bromberger & Matthews, 1996). During the past decade, ethnic, cultural, and racial differences in the informal caregiving experience have also attracted increasing interest with the majority of studies focusing on differences between the experience of caregivers of African-American and European-American backgrounds (Connell & Gibson, 1997; Janevic & Connell, 2001). Another study reported that African-American family caregivers tend to perceive the caregiving experience in general as less emotionally stressful (Dilworth-Anderson, Williams, & Gibson, 2002). These findings suggest that caregiver ethnicity also plays a role in the individual perception of their caregiving role. According to Pearlin’s model, contribute to the experience of informal caregiving.

Caregiver education level has also been researched as an important factor in the experience of caregiver burden. Higher caregiver education has been associated with both higher levels of burden (Cooney & Di, 1999), as well as lower levels of burden (Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). However, other studies of caregiver burden have indicated no relationship between level of education and psychosocial distress (Cooper, Balamurali, & Livingston, 2007). Thus, it is unclear how education level may be related to the experience of caregiver burden.

Some research has suggested that spousal caregivers exhibit higher levels of psychosocial distress and lower levels of well-being than other family caregivers, suggesting that relationship to the care recipient is an important variable (Schulz et al., 2007; Williams, 2005). Researchers have theorized that this relationship may originate from a number of factors. These factors include the fact that spouses provide more comprehensive care, maintain the caregiving role for longer periods of time, care for more impaired individuals, and spend more hours per week on caregiving tasks (Neal, Ingersoll-Dayton, & Starrels, 1997). The increased psychosocial distress among spousal caregivers, may be as a result of the previously discussed phenomena of emotional contagion. These findings highlight the often complicated relationships between variables that are related to the multi-faceted experience of informal caregiving. Caregiver research has focused attention on the on the identification of individuals at increased risk for experiencing psychosocial distress due to the caregiving role (Yee & Schulz, 2000; Young & Kahana, 1989). Pearlin's model represents one of those strides, as it offers clarity on this complex interplay between caregiving role and psychosocial distress.

This complex model is based on research that has identified caregivers who are especially prone to experiencing negative outcomes of informal caregiving. It has identified a number of personal resources that are particularly helpful for dealing with stress as a result of caregiving. Although the present research incorporates all six components of Pearlin's model, this treatise will focus on some of the most consistent and strongly supported findings within these domains, including caregiver gender, care recipient behavioural/and or emotional disturbances and patient's functional dependency.

2.9.3 Six-element model of caregiver burden and depression

Lazarus and Folkman's (1984) general model of stress and coping has influenced the formulation of several theories relating to the psychosocial distress caused by caregiving (Carruth, 1996; Schulz, Thomkins, Wood, & Decker, 1987). Pinquart and Sörensen (2005) proposed a six-element model of caregiver burden and depression (see Figure 1.2), which is reflective of the recent research carried out with regards to informal caregiving. As discussed in the previous chapter psychological distress is closely associated with caregiver burden (Nijboer et al., 1998; Kasuya et al., 2000; Lowery et al., 2000) and thus this model is deemed as offering a relevant perspective on caregiving burden and depression.

Figure 1.2 Pinquart and Sörensen's Six-element Model of Caregiver Burden and Depression

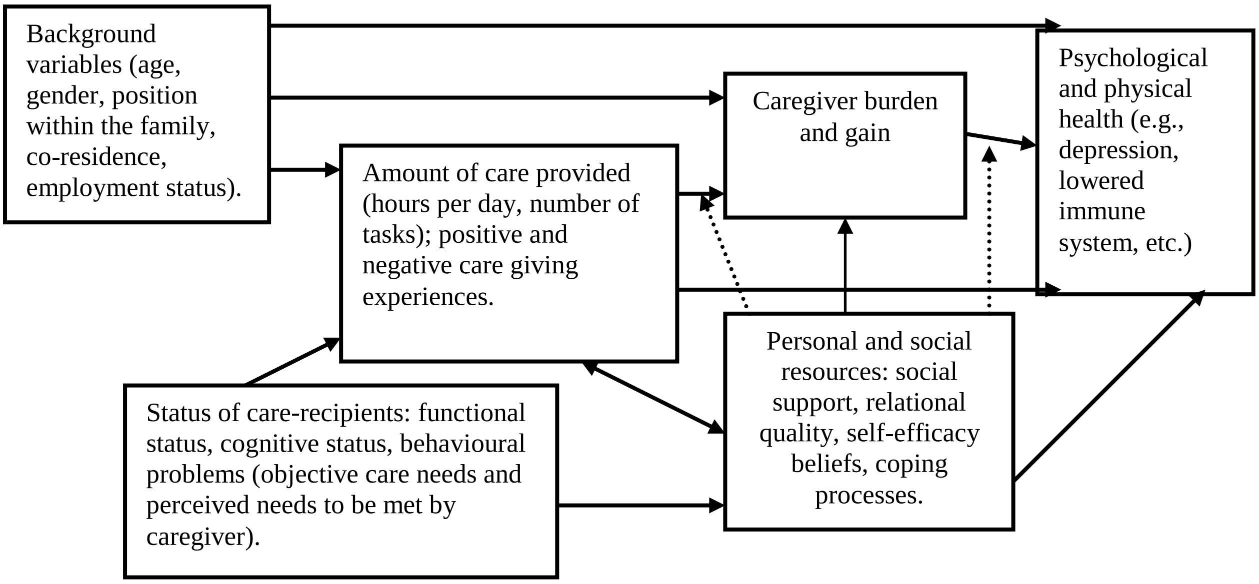


Figure 1.2 Model of caregiver burden and depression. Adapted from "Caregiving distress and psychological health of caregivers" by M. Pinquart, and S. Sörensen ,2005. Copyright 2005 by Nova Science Publishers, Inc.

Pinquart and Sörensen's (2005) model has sveral elements which are similar to that of Pearlin, however emphasis is placed on the whole process of caregiver stress, by placing emphasis on the caregiver burden. The theorists suggest that the level of care-recipient dependency and the amount of care provided will influence the availability of resources. High caregiving demands and high levels of care-recipient dependence may encourage caregivers to obtain resources, such as seeking and obtaining informal and formal support. On the other hand high caregiving demands and high levels of care-recipient dependence might equally well erode resources. Caregivers can thus experience either caregiver burden or gain (de-Graft Aikins et al., 2005; Teschendorf et al., 2007). For instance a caregiver may perceive their caregiving as affecting the quality of the relationhip with other relatives and friends due to the lack of time to cultivate these relations. This may contribute to the caregiver's experience of burden.

In this model psychological and social resources have a direct effect on outcome variables and a buffering effect on the relationship of objective stressors with caregiver burden, and the association of burden with general psychological and physical health. Pinquart and Sörensen (2005) also consider variables specific to the caregiving experience, such as burden and gain and general indicators of psychological and physical health such as caregiver depression or phsycial ill-health. Stressors are expected to have a direct and indirect effect on caregiver health, which is worsened by caregiver burden, but improved by caregiver gain.

Both caregiver burden and depression contribute to the level of caregiver coping. Therefore variables such as the status of the cancer patient, background variables, caregiver role demands, caregiver burden and gain, as well as personal and social resources might all impact on adult informal caregivers' ability to cope with their demanding "unexpected careers".

2.9.4 Lazarus and Folkman's stress and coping theory

There is consensus within literature that coping is a primary factor that has been found to mediate the interaction between stressful life events and outcomes of adaptation, such as depression, anxiety and psychological symptoms (Wade et al., 2001). There also appears to be an interest in the actual coping processes that individuals use to manage the demands of stressful events (Raina, 2004; Stajduhar, Fyles, & Barwich, 2008). This approach according to Kobasa, Maddi and Kahn (1982) is distinct from trait oriented approaches, which focus on personality dispositions from which coping processes are usually inferred, but not actually studied.

Lazarus (1993) asserts that despite different definitions of the stress process there are three key concepts. Firstly, there should be an internal or external causal agent present which is often referred to as either stress or stressor. Secondly, an evaluation should be carried out either through a cognitive or physiological process to which helps to distinguish the threatening from the benign. Thirdly, an intricate pattern of effects on the mind or body, referred to as the stress reaction may occur. Lastly, a coping process used by the mind should be used in order to deal with the threat.

Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986), assert that the critical difference between the trait-oriented and the process oriented approaches is the emphasis placed on the psychological and environmental context in which coping takes place. In the trait-oriented approach, it is assumed that coping is primarily an internal characteristic of the person, and variations in the stressful situation are of little importance (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). In contrast, the context is critical in the process-oriented approach because coping is assessed as a response to the psychological and environmental demands of specific stressful encounters. However, coping processes are usually assessed contextually, with few exceptions (Lechner, Carver, Antoni, Weaver, & Phillips, 2006).

The stress and coping process outlined by Lazarus and Folkman (1984) is subdivided into two processes. Namely; the cognitive appraisal portion, is a process through which an individual evaluates whether a specific encounter with the environment is relevant to his or her well-being. If the encounter is deemed relevant the individual then has to ascertain the particular ways in which it is relevant. There are two forms of cognitive appraisal (Lazarus & Folkman, 1984). The first is primary appraisal, where the individual evaluates whether he or she has anything at stake in this encounter. A caregiver might for instance be concerned about the potential harm or benefit with respect to their commitments, values, or goals. They may also wonder as to the health or well-being of a loved one. The second form of cognitive appraisal is secondary appraisal, which is made up of a process where the individual evaluates what if anything can be done to overcome or prevent harm or to improve the prospects for benefit (Lazarus & Folkman, 1984). Various coping options are assessed through this process, such as altering the situation, accepting it, seeking more information, or holding back from acting impulsively and in a counterproductive (maladaptive) way (Lazarus & Folkman, 1984).

Coping is defined as a person's constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person's resources (Lazarus & Folkman, 1984b). There are three key features of this definition. First, it is process driven, meaning that it centres around what the individual actually thinks and does in a particular stressful encounter, and the ways in which this changes as the encounter unfolds

(Lazarus & Folkman, 1984b). This concern with the process of coping is as previously stated in contrast with trait approaches, which are concerned with what the person usually does, and hence emphasize stability rather than change. Secondly, coping is viewed as being contextual, that is, influenced by the individual's appraisal of the actual demands in the encounter and resources for managing them (Lazarus & Folkman, 1984b). The emphasis on context means that specific person and situation variables together shape coping efforts. Thirdly, this definition does not make any prior assumptions about what makes coping good or bad; coping is defined plainly as an individual's efforts to manage demands, whether or not the efforts are successful (Lazarus & Folkman, 1984b).

Both primary and secondary appraisals converge to determine whether the person-environment transaction is regarded as significant for well-being, and if so, whether it is primarily threatening (containing the possibility of harm or loss), or challenging (holding the possibility of mastery or benefit). These processes are thus pivotal to the mediation of stressful person-environment interaction as well as the psychosocial outcomes of that interaction (Folkman et al., 1986).

One of the goals of coping is to manage the immediate outcome of an encounter. Immediate outcomes according to Lazarus et al. (1986) refers to the person's judgment of the extent to which the encounter was resolved successfully. The authors assert that the overall judgment is based on the individual’s values and goals, and his or her expectations concerning various aspects of the stressful encounter (Lazarus et al., 1986). For example, even though there has not been a resolution of the problem causing distress, an outcome can be evaluated favourably if the person feels that the demands of the encounter were managed as well as could have been expected. It may also be judged as unfavourable if the resolution was not consistent with some values and goals, to the extent that it is less than what the person thought could be achieved, or creates additional conflicts in the person's social context (Lazarus et al., 1986). This is despite the fact that the problem causing distress may have been resolved. Coping goals such as the one that has been discussed are achieved through certain coping strategies (Lazarus et al., 1986). This principle can be applied to cancer in the sense that even though cancer patients sometimes experience nausea despite treatment efforts to decrease this side effect, caregivers may evaluate their symptom management as successful if they are able to offer emotional support to the patient (Hofmann & Kashdan, 2009).

2.9.5 Coping strategies

Several classification systems of coping strategies have been proposed (Skinner, Edge, Altman, & Sherwood, 2003; Hofmann & Kashdan, 2009). Among them are the three strategies of coping with distress, which include strategies aimed at re-adjusting in order to adapt successfully to situational demands (Hofmann & Kashdan, 2009). The second type of coping strategies are characterized by their focus on concealment or suppression of distress and the third type of coping strategies enable individuals to tolerate and accept emotions, including unwanted and aversive reactions.

Connor-Smith, Compas, Wadsworth, Thomsen and Saltzman (2000) suggest the categorization of coping strategies into approach or avoidant strategies. The authors explain that, approach strategies involve direct efforts to change the stressful situation and include problem solving, seeking support and acceptance. Avoidant strategies on the other hand are characterized by the absence of efforts to alter the situation and include denial, avoidance and wishful thinking. Connor-Smith et al. (2000) further state that studies of coping in family caregivers indicate that better adjustment is associated with less reliance on avoidant coping strategies and greater use of approach strategies.

The most widely used categorization of coping strategies is that of Lazarus and Folkman (1984), who identified two types of coping strategies namely, emotion-focused and problem-focused coping. Emotion-focused coping consists of behavioural and cognitive strategies aimed at controlling undesirable feelings associated with stressful situations. Passive avoidant emotion-focused strategies such as self blame, distancing and wishful thinking have been associated with poor stress outcomes (Epping-Jordan, Compas, & Osowiecki, 1999),whereas more constructive emotion-focused strategies such as reappraisal (Gross & John, 2003) and acceptance are thought to be more adaptive (Stone, Kennedy-Moore, & Neale, 1995; Gross & John, 2003).

Problem-focused coping refers to active behavioural strategies such as planning and information seeking (Lazarus & Folkman, 1984). In general, this way of coping has been considered adaptive because it involves efforts to act directly on the source of stress (Marin, Holtzman, & DeLongis, 2007). Most notably, problem-focused strategies have been found to be more beneficial when dealing with highly controllable events (e.g., academic failure, Band & Weisz, 1988), as compared to those events over which it is more difficult to exercise control (e.g., being diagnosed with cancer; Weisz, McCabe, & Dennig, 1994). The effectiveness of problem-focused strategies thus appears to be situation specific.

Relationship-focused coping has been described as a coping strategy to complement those outlined by Lazarus and Folkman (1984). Relationship-focused coping thus refers to modes of coping aimed at managing, preserving, or maintaining relationships during stressful periods (O'Brien & DeLongis, 1997). This type of strategy is viewed as being particularly effective in relation to communal stressors (Marin et al., 2007). For example, coping attempts that focus on maintaining relationships in times of parenting stress, (e.g., empathic responding) especially during children's adolescence, may decrease levels of family tension. Empathic coping has also been associated with increased satisfaction among caregivers to spouses with Alzheimer's disease (Kramer, 1993).

The abovementioned coping strategies may lead to the individual's adaptation to cancer caregiving on different levels, however if the adaptation level does not meet the goal, then another cycle of the coping process will continue.

2.9.6 Sense of coherence theory

Coping resources are relatively stable characteristics of a person's internal (e.g. character) and external (e.g. social support) environments. Coping resources also refer to what is available to individuals when they develop coping strategies (Moos & Billings, 1982). Specific psychological resources (e.g., personality characteristics) may influence caregiver outcomes (Pearlin & Schooler, 1978). These resources may include, mastery, neuroticism and extraversion, which according to Pearlin, Lieberman, Menaghan and Mullan (1981), appear to be central constructs in several trait theories of personality and are associated with caregiving. The authors further argue that these traits seem to be associated, both theoretically and practically, with psychosocial outcomes (e.g. depression), especially during stressful situations.

In a study carried out by Nijboer, Tempelaar, Triemstra, van den Bos and Sanderman, (2000), it was reported that with respect to caregiver's depression and personality characteristics, three significant moderating effects of mastery were observed. Caregivers who have a strong sense of mastery whose care recipients reported a high initial score on depression showed a lower level of depression over time. Caregivers with a strong sense of mastery who also derived significant levels of self-esteem from caregiving reported the lowest levels of depression. In addition, caregivers with a high mastery who perceived little disruption in their daily schedule reported the lowest levels of depression over time. Moderating effects were observed to play a role within the caregiving process, especially with regard to positive aspects of social support and mastery.

Sense of coherence (SOC) is a key construct relating to coping as discussed within the previous chapter. The concept of sense of coherence is based on Antonovsky's salutogenic theory, which argues that the health of individuals can be viewed as a continuum and focuses on over-all physiological and psychosocial well-being (Antonovsky, 1979). The salutogenic theory is the contrary of pathogenic paradigm where the focus is predominantly on obstacles and deficits (Lindström & Eriksson, 2005). Sense of coherence is categorized as part of general resistance resources which are defined as physiological, material and psychosocial factors. These factors aid individuals to perceive their lives as being constant, ordered and reasonable. Generalized resistance resources, include any resources that neutralize stressors, for example material resources, knowledge, social support and religion.

Generalized resistance forces are key in determining if a stressful situation will result in significant weakening of the individual's sense of coherence, which in turn may negatively impact well-being (Wolff & Ratner, 1999).

Sense of coherence is thus the individual's orientation to life, which may have an influence on the manner in which stressful encounters are perceived (Lindström & Eriksson, 2003). Research has shown that this way of viewing life is associated with the mediation of the psychosocial effect of difficult life situation including illness (Germano, 1996; Weissbecker et al., 2002; Wolff & Ratner, 1999). According to Antonovsky (1987) the carer's perception is dependant on the three elements which underlie individual's sense of coherence namely; comprehensibility, manageability, and meaningfulness.

Individuals with a strong sense of coherence may thus view stimuli experienced as predictable and explainable and may accordingly have resources at their disposal to meet the demands presented to them through this stimuli (Antonovsky, 1987). Such individuals may further believe that these demands are challenges which are worthy of investment and engagement. The person with a strong sense of coherence also has the ability to select the most suitable coping strategy to deal with the stressor which they are faced with at the time. Handling stressors well, a person with a strong sense of coherence will reinforce and/or improve their overall well-being.

According to Lazarus (1993), there are several personality traits which have been found to be linked to resilience including, optimism, constructive thinking, hardiness, hope, learnt resourcefulness and sense of coherence. Sense of coherence is strongly and negatively associated with anxiety, anger, burnout, demoralization, hostility, hopelessness, depression, perceived stressors, and post-traumatic stress disorder. Eriksson and Lindström (2005) asserts that the stronger sense of coherence, the better perceived health. Geyer (1997) further affirms the importance of this concept with his findings, which reflect that sense of coherence and depression are closely associated and negatively correlated.

2.10 Summary

This chapter has looked at the broad issues regarding informal caregiving of the chronically ill, in order to gain a better understanding of the context of cancer caregiving. Cancer caregiving has been reviewed within the formal context and a discussion of psychosocial affects of cancer on formal caregivers was done in order to establish the unique challenges faced by such carers. Informal caregiving of cancer patients was also reviewed in terms of the novel role which is being assumed by these individuals, including the burden of caregiving. The psychosocial distress of informal caregivers was also explored. The aspect of informal caregiver coping was briefly discussed.

The second portion of this chapter outlined the theoretical perspectives underlying the phenomena regarding stress and coping strategies. The next chapter will outline the research methodology of this research with an overview of the research procedures, research design and description of the research instruments used, as well as the methods of data analysis.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

Chapter Two offered an overview of the literature on the different dimensions of caregiver distress and the coping strategies used by informal caregivers. The chapter outlined previous findings on the distress and coping experienced by various caregivers across different caregiving contexts within the realm of chronic illness. This was followed by a more focused look at distress and coping amongst cancer patients and caregivers. The role and burden experienced by caregivers was explored. The aforementioned section of the chapter included a review of literature on the psychological effects of cancer on the patient, formal caregiver and finally the focus of the current study which is the informal caregiver. Additionally, a delineation of literature on various theoretical perspectives was provided and included; the emotional contagion theory, Pearlin’s model of caregiver stress, the six-element model of burden and depression, Lazarus and Folkman’s stress and coping theory, and Antonovsky’s sense of coherence theory.

Given this background literature review, the current chapter aims at providing a description of the research methods used to meet the objectives of this study. The research design, sample and sampling frame, research procedures and research instruments and statistical analysis methods were outlined.

3.2 Research design

This research is both quantitative and exploratory in nature. A quantitative approach was chosen for this research due to its emphasis on the measurement of constructs (e.g. distress). Correlation is another focus of quantitative research which was central to this research, as the research sought to explore possible relationships between variables such as distress and coping strategies (Bryman, 2004). The research is exploratory due to the fact that it is looking at an area of research that has not been investigated previously within the Namibian context.

The research is non-experimental and thus describes a set of variables (i.e. distress and coping strategies used) as they occur within their natural environment (Breakwell, Hammond, Fife-Schaw, & Smaith, 2006). A survey method of collecting data was used as it provided a way to gather fairly sensitive data as efficiently as possible. The survey method took the form of five self-report questionnaires together with a demographic questionnaire. A correlational research design was used within this exploratory research, as it measures how strong two or more variables are related to each other (Banyard & Grayson, 2000).

3.3 Participants

The research sample was made up of adult family caregivers (18 years and above) of cancer patients. The inclusion criteria were individuals who are socially bonded to the cancer patient (e.g. wife, husband, mother, father, partner, son, daughter, neighbour, friend) and fulfilling the role of an informal caregiver to the cancer patient without getting paid for their caregiving tasks. The care recipients within the context of this research were individuals diagnosed with various forms of cancer. The informal caregivers within this research offered some form of instrumental (e.g. driving to doctor's appointments), informational (e.g. searching for treatment side effects on the internet) and/or emotional support to the patient diagnosed with cancer. Formal and paid caregivers were excluded from this research.

A convenience sample was used. According to Welman and Kruger (2001), this is a non-probability sampling technique. It uses random selection in order to gather the most apt collection of members of the population. Thus individuals who were available and willing to respond were included in the research, if they met the inclusion criteria. The Dr. A. Bernard May Cancer Care Centre in Windhoek (Namibia) was selected as a source of participants because it is the primary state provider of oncology treatment in the country. Many cancer patients (often accompanied by their informal caregivers) come from all 13 regions of Namibia to receive treatment at this oncology clinic. The aforementioned implies that it offered greater control of biased sampling as it gave a greater representation of the particular population. An attempt was thus made to control for biased sampling which has been identified as one of the major challenges inherent to convenience sampling (Gravetter & Forzano, 2006). In order to increase the sample size participants were also recruited through the Cancer Association of Namibia. Sixty-five (65) adult family caregivers of cancer patients in treatment were selected for participation.

3.4 Procedures

Approval of the research was obtained from the Post-Graduate Studies Committee (PGSC) of the University of Namibia. Authorization to collect data at the Windhoek Central Hospital was obtained from the Ministry of Health and Social Services' research unit. The oncologists and oncology nurses at the Dr A. Bernard May Cancer Care Centre were briefed on the objectives of the research before commencement of the data collection. The oncology staff or researcher identified potential research participants. Participants were given an information letter outlining the purpose and nature of the study (see Appendix A) and written informed consent was sought. Questionnaires were distributed to caregivers at the Dr. A. Bernard May Cancer Care Centre waiting room at the Windhoek Central Hospital as well as on the fourth floor of the Windhoek Central Hospital (hospital floor designated for most cancer in-patients). Participants received assistance in completing the questionnaires from the researcher as well as nurses and administrators.

In keeping with the American Psychology Association (APA, 2000) ethical guidelines in research, all questionnaires were completed anonymously.

3.5 Research Instruments

In keeping with a quantitative research design and the objectives of the study, a socio-demographic questionnaire and four (4) measures were used. The shortest version of each of the four measures was chosen in order to mitigate the collective completion times for all four measures.

3.5.1 Socio-demographic questionnaire

A self-designed socio-demographic questionnaire was used to obtain information regarding participants' age, gender, marital status, current employment status, socio-economic status, relationship to cancer patient, level of education, diagnosis of the care recipient and time since diagnosis (see Appendix B).

3.5.2 The Distress Thermometer (DT)

The Distress Thermometer (DT) is a single-item self-report, visual analogue instrument. The DT is in the form of a graduated thermometer. Participants are asked to rate their distress on an 11 point scale which ranges from 0 (no distress) to 10 (extreme distress) as seen in Appendix C. Presenting the DT as a graded scale offers researchers and oncology practitioners a way to measure the severity of the distress experienced by individuals. The DT was originally designed by Roth et al. (1998) to screen for global psychological distress in cancer patients. This instrument has been used in cancer caregiver research for the purpose of screening for psychological distress in informal caregivers of cancer patients (Bornena & Ingham, 2005). For the purpose of this research, the DT was used to screen for psychological distress in informal caregivers of cancer patients.

Owing to its ultra-short nature and ease of administration and scoring, it can lead to a greater response rate (Larouche & Edgar, 2004). The use of the DT was a practically prudent choice due to the fact that participants within the study were required to complete the questionnaires within a short period of time (e.g., whilst in the oncology clinic waiting room). Since its creation in 1998, the DT has gained widespread international popularity in its use in both clinical practice and research, and it has been used in more than 50 publications (Mitchell, 2007). The National Comprehensive Cancer Network (NCCN, 2007) has recommended the DT as a key screening measure of distress.

The term “distress”, as it is used within the context of the DT, refers to a range of psychological, spiritual and social concerns. These concerns may include feelings of vulnerability, sadness, fear, depression, generalized anxiety, panic, isolation or experience of a sense of spiritual crisis (Holland, 1999; Kelly, McClement, & Chochinov, 2006; NCCN, 2007). The word distress is used within oncology settings because it does not carry the stigmatising associations which are often linked to psychiatric diagnoses (Larouche & Edgar, 2004).

This study used a DT cut-off of four (4), which means that all those individuals who scored four or above met the standard cut-off. The DT has been used in caregiver as well as patient research and the cut-offs of four and five have been reported to be sensitive in the screening of distress (Mitchell, 2007; Roth et a., 1998; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). This instrument has previously been used together with measures of distress, such as the Hospital Anxiety and Depression Scale (HADS) (Jacobsen et al., 2005; Mitchell, 2007). The DT thus correlates strongly with other instruments which measure distress (Roth el al., 1998; Trask et al., 2002). The DT has been used within the Namibian context among breast and cervical cancer patients (Shino, 2010).

3.5.3 Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS), which was developed by Zigmond and Snaith (1983), is a self-report instrument that measures anxiety and depression. The total score of the HADS has been used in studies as a measure for psychological distress (Razavi, Delvaux, Farvacques, & Robaye, 1990; Ramirez, Richards, Jarrett, & Fentiman, 1995). The HADS was designed for use among patients in hospital or clinic settings (Zigmond & Snaith, 1983). It is made up of 14 items, comprised of two sub-scales (anxiety and depression) of 7 items each (see Appendix D). The respondents are asked to indicate which of four options ranging from 0 to 3 in each sub-scale they most relate to. The scores range from 0 to 21 for each subscale and from 0 to 42 for the total scale. The instrument takes on average less than 10 minutes to complete.

Several psycho-social oncology studies have suggested the use of the total score on all 14 items to be used as a global score for psychological distress (Mitchell, 2007; Ibbotson, Maguire, Selby, Priestman, & Wallace, 1994; Lewis & Wessley, 1990). The HADS has been used as a screening and research tool among patients and caregivers in oncology settings (Herrmann, 1996; Kelly, McClement, & Chochinov, 2006; Nieboer et al., 1998). The HADS was designed in the 1980's and has since been widely used internationally. It has over 33 different language translations, which may be a reflection of the strength of the measure as well as its cross cultural applicability (Bedford, 1997).

The psychometric properties of the HADS are invariable enough to withstand situational influences (Hermann, 1996). Studies conducted in African oncology settings found the HADS to be reliable as well as valid (Boermeester & Berard, 1998; Abiodun, 1994). The HADS has previously been used within the Namibian context with cancer patients (Shino, 2010).

The anxiety subscale (HADS-A) cut-off used in this study was 8 and the depression subscale (HADS-D) cut-off used was also 8 (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmond, & Snaith, 1983). A cut-off of 15 for the over-all HADS (all 14-items) was used in this study because it has been found to be indicative of psychological distress (Jacobsen et al., 2005). A study carried out by Rodgers, Martin, Morse, Kendell, & Verrill (2005), reported a Cronbach's alpha of 0.85 for the over-all HADS as well as, 0.79 and 0.87 for the HADS-A and HADS-D respectively.

3.5.4 The Brief Coping With Problems Experienced Inventory (Brief COPE)

The Brief Coping With Problems Experienced Inventory (Brief COPE) (Carver, 1997) is made up of 28 items, which are divided into 14 sub-scales of two items each as outlined in Appendix E. The Brief COPE takes an average of 10 minutes to complete (Carver, 1997). It is designed to assess coping strategies used by individuals in response to stress (Carver & Scheier, 1994; Greer, 2007). The Brief COPE is derived from the original sixty-item measure, the COPE Inventory and its construction was guided by Lazarus' model of stress (Carver, Scheier, & Weintraub, 1989).

The sub-scale measures of the Brief COPE are as follows: self-distraction, active coping, denial, substance use, behavioural disengagement, venting, planning, positive reframing, self-blame, humour, acceptance, use of instrumental support, use of emotional support and religion (Carver,1997). These coping strategies are associated with three latent factors that are going to be explored in this study. The latent factors are; emotion-focused coping (e.g. venting), problem-focused coping (e.g. seeking instrumental social support) and maladaptive efforts or those that serve to hinder or impede progress in resolving stressful situations (e.g. substance use) (Carver, Scheier, & Weintraub, 1989). The possible responses range from 0 (I haven't been doing this at all) to 3 (I've been doing this a lot). The Brief COPE looks at coping responses and has been used in previous caregiver coping research (Marin, Holtzman, DeLongis & Robinson, 2007; Carver, 1997).

The higher scores on the sub-scales indicate greater use of that particular coping strategy. The Brief COPE's overall factor structure has been validated in a number of research studies and the measure's convergent and discriminate validity have been consistently established (Carver, Scheier, & Weintraub, 1989; Deisinger, Cassisi, & Whitaker, 1996; Litman, 2006). Each scale was used to create second order factors which was used as predictor factors and the data from research by Carver and colleagues (1989) were then used to determine the composition of the higher-order factors. The Cronbach's alpha of the 14 subscales of the Brief COPE, ranges from 0.50 to 0.82 (Carver, 1997).

3.5.5 The Sense of Coherence Scale (SOC)

The 13 item version of the Sense of Coherence Scale (SOC) assesses individual's confidence in his/her ability to manage the experience of tension (see Appendix F). It also measures self-belief in assessing internal and external resources as well as the mobilization of resources for health promotion purposes thus promoting better coping and lowered psychological morbidity (Antonovsky, 1993). Studies have shown that individuals with a strong sense of coherence tend to manage life stressors better and stay well, whereas individuals with a lower sense of coherence tend to have a greater vulnerability to over-all emotional and physical ill health (Feldt, 1997; Antonovsky, 1993; Siglen, Bjorvatn, Engelbretsen, Burglund & Natvig, 2007).

The scale consists of five Comprehensibility items, four Manageability items, and four Meaningfulness items (Antonovsky, 1993). With regards to the three overall Sense of Coherence scale dimensions, contention seems to exist in terms of whether the these components should be viewed as unidimentionally or as being composed of one over-all factor (Germano, 1996; Eriksson & Lindstrom, 2005). The concept of separate structures has been argued against by several studies (Kravetz, Drory, & Florian, 1993; Frenz, Carey & Jorgensen, 1993; Germano, 1996).

Each item of the sense of coherence scale is presented on a 7-point Likert scale, with scores ranging from 13 to 91. The response range for the scale is from 1 (weak SOC) to 7 (strong SOC). Five of the items are negatively stated and reversed in scoring so that a high score always indicates a stronger SOC (Antonovsky, 1993).

The SOC scale seems to be a reliable, valid, and cross culturally applicable instrument measuring how people manage stressful situations and stay well (Eriksson & Lindström, 2005). To the knowledge of the researcher SOC scale has not been used within the Namibian oncology setting, but has been used in several studies within the African context (Rothmann, Jackson & Kruger, 2003; Rothmann & Strijdom, 2002; Marié et al., 2010). A systematic review by Eriksson and Lindström (2005) of studies carried out across 32 countries found that 127 of those, which made use of the 13-item SOC scale found that the reliability coefficients range from 0.70 to 0.92. A South African study carried out by Strümpfer and Wissing (1998) reviewed 27 South African studies making use of the English version of the SOC scale and reported reliability coefficients ranging from 0.87 to 0.95. With regards to its specific use within the context of caregiving, there have been documented research studies in the context of informal caregiving (Gallagher, Morton, Baro & Haepers, 1994; Schroder & Schwarzer, 2001).

3.5.6 Zarit Burden Interview (ZBI)

The instrument was originally developed to measure caregiver burden within the context of dementia (Zarit & Zarit,1987). The instrument is used to measure caregiver burden within a wide spectrum of conditions and has been used in previous informal cancer caregiver research (Siegert, Jackson, Tennant, & Turner-Stokes, 2010). The interview consists of 22-items, all measuring different dimensions of burden (see Appendix G). Factor analysis research carried out by Siegert et al. (2010) outline two broad factors measured by this instrument. These two factors reflect psychological distress (i.e. personal strain) and the general impact on caregiver's life (i.e. role strain). The measured dimensions of the instrument include; personal strain, financial and health strain, role strain and management of care (Zarit, 1984).

The Zarit Burden Interview (ZBI) contains 11 items within the full 22-items that can provide interval scale scores on the two dimensions of burden (Siegert et al., 2010). The two dimensions of the ZBI (i.e. personal strain and role strain) are functional within research and the clinical context. The ZBI gives researchers an opportunity to explore how these two different dimensions of burden can mediate the impact of the care recipient's dependency on the quality of life of the caregiver (Tang & McCorkle, 2002). It may also help to identify different mechanisms for supporting the caregiver in their role. It also raises the possibility of routinely assessing personal strain and role strain in caregivers. A high level of personal strain might for instance indicate a need for supportive counselling or cognitive-behavioural therapy aimed at helping the caregiver manage strong emotional responses, such as anger and anxiety. In contrast, a high level of role strain might suggest a need for additional respite care or home support aimed at freeing up the caregiver's time so as to allow them to fulfil their other roles and tasks in life.

The items are rated on a 5 point Likert scale ranging from 0 (meaning the individual never has that particular experience) to 4 (meaning the individual has that particular experience everyday). The total score of burden is obtained by adding the scores of all the items with a range of 0 to 88, with higher scores indicating greater burden. The ZBI has good concurrent validity and internal consistencies ranging from 0.88 to 0.91 (Hartke & King, 2002).

3.6 Statistical Analysis

In order to fully understand the distress experienced and coping strategies used by adult family caregivers, quantitative methods were employed to analyze the data. Descriptive statistics (e.g. mean, standard deviation and frequencies) were used in order to describe the characteristics of the variables in relation to the research sample and in order to meet the specific research objectives outlined earlier. The measurements were analysed using SPSS Version 18 to determine whether any patterns of relationship exist between the variables as well as to measure the strength of the relationship (i.e. to see if the relationship is significant or not).

The services of a statistical analyst were obtained to verify the correctness and validity of the statistical analyses. Correlations were used to explore the strength of the relationship between variables (Pallant, 2005).

3.7 Summary

This chapter was aimed at providing a clear outline of the methodological approach of this quantitative research study. The aims of the study were briefly delineated in order to serve as a plat form from which to discuss the different measures which were used to measure the salient variables of this study. The practical aspects of carrying out this research were also outlined by looking at the procedures followed for obtaining participants as well as the inclusion and exclusion criteria used to get the research sample. Finally, the process of statistical analysis was presented. The next chapter will present the results of the research, followed by discussion of the results in Chapter Five.

CHAPTER FOUR

RESULTS

4.1 Introduction

The previous chapter focused on the methodology followed in this research. Various measures of key variables (i.e. distress, anxiety, depression, burden, coping strategies and sense of coherence) were analysed in order to quantify the collected data. This chapter offers a description of the results obtained. The response rate is described first and thereafter demographic data are presented. The scores which were obtained through the various measures (i.e. DT, HADS, ZBI, Brief COPE and SOC scale) will then be outlined. In accordance with the specific aims outlined in Chapter One, the relationship between the variables will be outlined.

4.2 Demographic descriptive results

Of the 65 participants 56 were female and nine were male (n = 56 females and n = 9 males). The mean age of participants was 40.27 years (SD = 11.53). The youngest participant was 23 years old and the oldest participant in the sample was 70 years old. With regards to marital status, 41.5% of participants were single, 38.5% married, 13.8% living with a partner and 6.2% were widowed. The sample was composed of individuals who were employed full-time (47.7%), some participants reported being unemployed (12.3%), self-employed (12.3%) or retired (9.2%) (see Figure 4.1). Participants with limited education (ranging from no schooling to some high school education) accounted for 35.4% of the sample. The majority of participants (55.4%) of participants reported their socio-economic status as being low to middle income. The mean age of the cancer patients who were under the care of the family caregivers was reported as being 52.6 years (SD = 17.72). Figure 4.2 shows the cancer sites as reported by caregivers: breast (23.1%), colon (10.8%), lung (4.6%), prostate (3.1%), other sites (43.1%) and the pancreas (1.5%), lymphoma (1.5%) and cervix (1.5%).

Figure 4.1 Caregiver's occupations

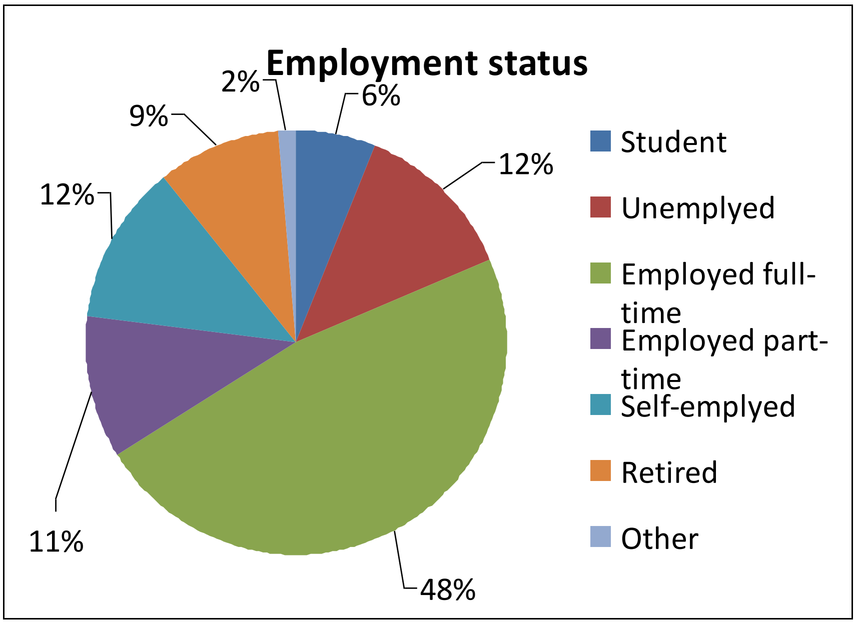
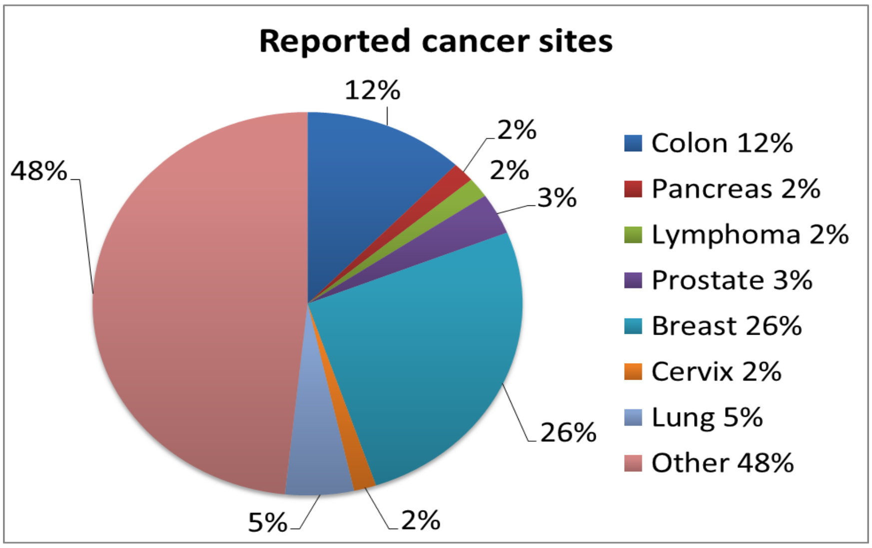
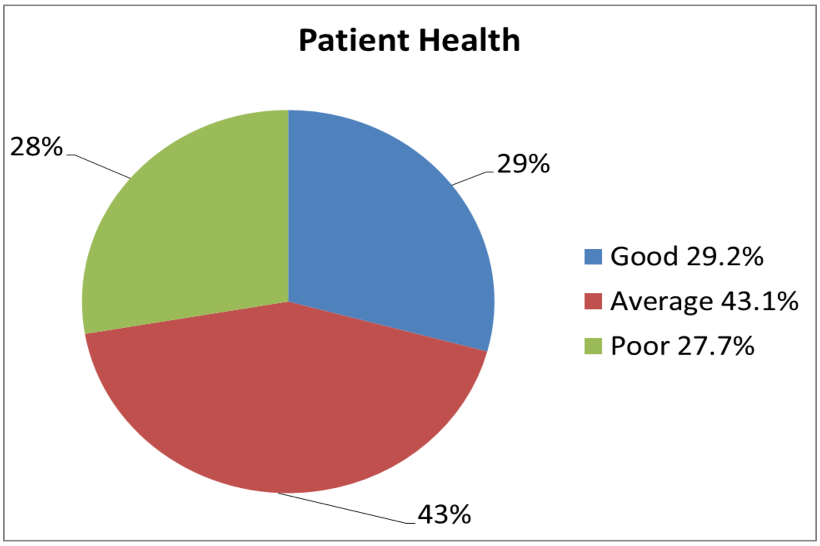


Figure 4.2 Types of Cancer Diagnoses



As depicted in Figure 4.3, caregivers rated patients' health as being average (43.1%), 29.2% described patient's over-all health as being good (29.2%) and 27.7% as poor. When describing their relationship to the care recipient (i.e. cancer patient), 20% (n = 13) reported being the mother of the care recipient, sisters made up 10.8% (n = 7) of the participants. Grand-mothers (n = 5), brothers (n = 5) and fathers (n = 5) made up 7.7% of the sample respectively. The duration of care ranged from less than one year (30.8%) to more than ten years (3.1%). Sixty percent (60%) of participants reported that they had not received previous counselling in the past.

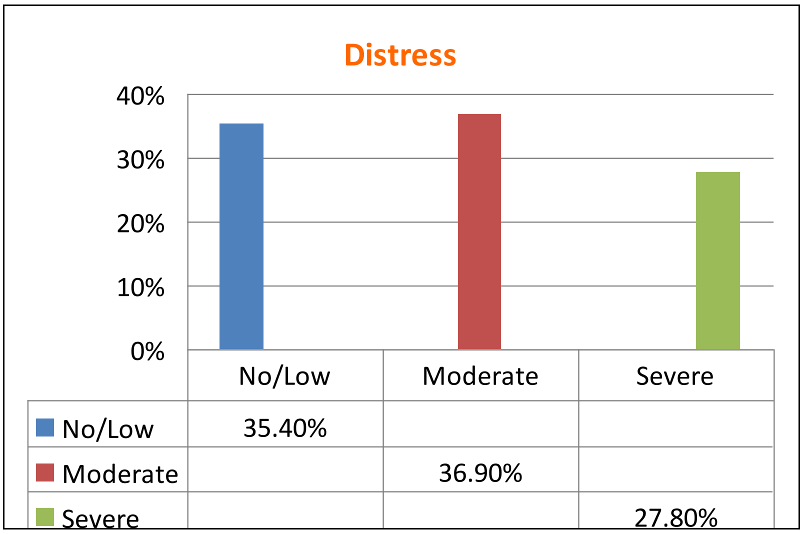
Figure 4.3 Health assessment of cancer patients made by caregivers



4.3 Caregiver distress

The first defined aim of the research was to explore global psychological distress of informal caregivers. Participants gave self-reports of their distress using the Distress Thermometer. Participants rated their distress ranging from no distress (0) to extreme distress (10) (see Figure 4.4.). The mean distress reported by participants was 4.88 (SD = 2.74). The participants who met the distress cut-off score of 4, made up 64.7% (n = 42) of the sample.

Figure 4.4 Psychological distress experienced by informal caregivers

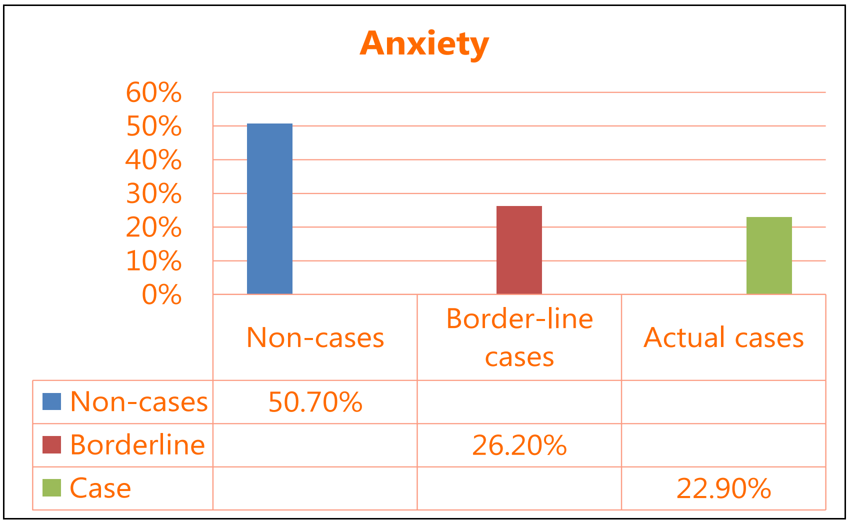


The global score of the Hospital Anxiety and Depression Scale (HADS) was also used in this research as a measure of psychological distress (Razavi, Delvaux, Farvacques, & Robaye, 1990; Ramirez, Richards, Jarrett, & Fentiman, 1995). The mean score for the over-all HADS score was 18.64 (SD = 5.64). The mean score meets the cut-off score of 15 set in this study and others (Jacobsen et al., 2005). The total proportion of the sample that met the cut-off is 56.9% (n = 37) of all participants. Psychological distress as measured by the Distress Thermometer as well as the HADS over-all score both indicate significant distress within this sample.

4.4 Caregiver distress and anxiety

The second specific aim of this research was the evaluation of the relationship between caregiver distress and anxiety. Anxiety was measured through the use of the HADS anxiety subscale. The anxiety subscale was scored using the protocol set forth by Snaith and Zigmund (1983), in which a score of 7 or less was categorized as being a non-case. Scores ranging from 8 - 10 are deemed as border-line cases and scores of 11 and more are actual cases. Non-cases made up 50.7% of the sample, whereas borderline cases (26.2%) and actual cases (22.9%) accounted for the rest of the reported cases (see Figure 4.5). The mean for the HADS-anxiety subscale was 7.88.

Figure 4.5 Anxiety experienced by caregivers



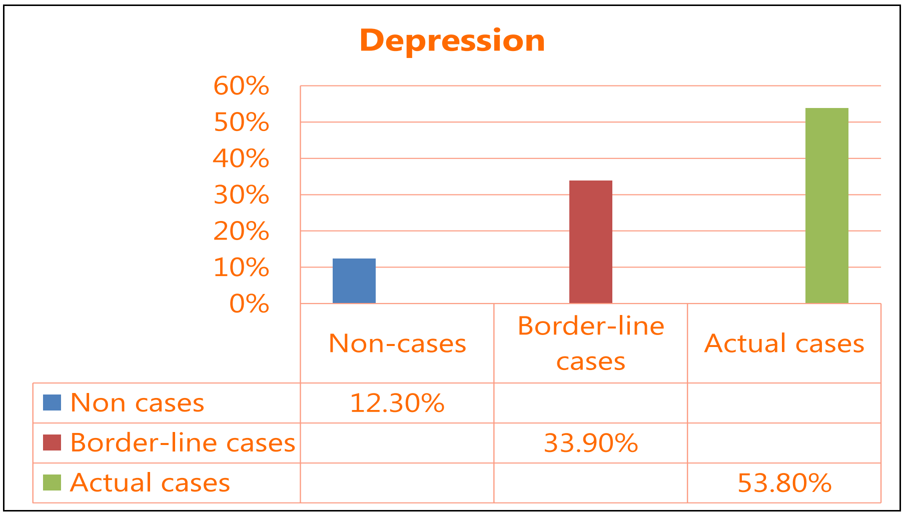
Bivariate correlations were conducted in order to evaluate the relationship between psychological distress (as assessed through the use of the DT) and anxiety (as measured by the HADS-Anxiety). Effect sizes (Cohen, 1988 as cited in Pallant, 2010) were used in the assessment of the strength of correlations as well as statistical significance in order to determine the significance of the association. According to Cohen (1988 as cited in Pallant, 2010), a correlation of r = .10 to .29 are indicative of a small (weak) correlation, a medium (moderate) correlation is indicated by r = .30

to .49 whereas a range of r = .50 to 1.0 shows a large (strong) correlation. Preliminary analyses were performed in order to ensure that there were no violations of the assumptions of normality, linearity and homoscedasticity. A significant and moderate positive relationship between distress and anxiety was found, r = .46, n = 65, p < .05.

4.5 Distress and Depression

The third specific aim of this research was to examine the relationship between psychological distress and depression. The mean HADS-Depression score 10.76 (SD = 2.45). Figure 4.6 indicates that 12.3 % (n = 8) of the cases fall under the non-case classification, 33.9% (n = 22) are categorised as border-line cases and 53.8% (n = 35) fall under the true case classification when using the criterion suggested by Snaith and Zigmund (1983).

Figure 4.6 Depression experienced by caregivers



The association between distress (as measured by the DT) and depression (as measured by the HADS-Depression) was evaluated using Pearson product-moment correlation coefficient. A significant and positive, moderate correlation between distress and depression was found, r = .36, n = 65, p < .05.

4.6 Caregiver burden

The evaluation of the burden experienced by informal caregivers was the fourth specific aim of this research. The measurement used to quantify burden was the Zarit Burden Interview. The categories outlined by Hebert, Bravo, and Preville (2000) suggest that scores between 0 and 21 indicate little or no burden, 21 to 40 is indicative of mild to moderate burden, 41 to 60 suggests moderate to severe burden and 61 to 88 is severe burden. The results show that 44.3% of participants experienced little to no burden, 41.5% of participants showed mild to moderate burden and 15% reported moderate to severe burden. The cut-off that was used in this research is 25 and the mean of the research was 25.94 (SD = 14.13). The mean obtained in this research has been suggested to be indicative of severe burden (Schreiner, Morimoto, Arai, & Zarit, 2006).

4.7 Caregiver burden and distress

The fifth specific aim of this research was to describe the relationship between informal caregiver’s distress and the burden they experience. A bivariate analysis was used in order to determine the association between distress (as measured by the Distress Thermometer) and caregiver burden (as measured by the Zarit Burden Interview). The Pearson product moment correlation coefficient showed a significant, moderate, and positive correlation between caregiver burden and distress, r = .37, n = 65, p < .05. This indicates that an increase of burden is associated with an increase in distress experienced by informal caregivers.

4.8 Coping strategies used by informal caregivers

The sixth specific aim of the current research was to explore the coping strategies used by informal caregivers. It has been asserted in literature that coping strategies are generally evaluated according to the frequency with which they occur in a particular sample (Chronister & Chan, 2006). Table 4.1 shows that the coping strategy used most commonly was substance use, followed by humour, behavioural disengagement, self-blame, religion, use of instrumental support and acceptance. The mean scores of the coping strategies show that use of emotional support and acceptance were used to a greater extent by participants. Other most recurrently used coping strategies include use of instrumental support, positive reframing, active coping, planning, self-distraction (see Table 4.1). Frequency of the coping strategies are indicative of the number of individuals who reported the use of certain coping strategies and the means show the extent (i.e. repeated use) to which the coping strategies were used on average by participants.

Table 4.1 Descriptive for coping strategies used (n = 65)

Coping strategy	Frequency	Mean	SD
Substance use	52	2.29	.700
Humour	46	2.58	1.16
Behavioural disengagement	31	3.15	1.67
Self-blame	30	2.92	1.35
Religion	28	6.22	2.30
Instrumental support	26	6.00	2.10
Acceptance	23	6.31	2.10
Active coping	22	5.75	1.75
Emotional support	21	6.31	1.66
Positive reframing	20	5.86	1.65
Planning	17	5.71	1.87
Venting	16	4.05	1.87
Denial	16	4.32	1.84
Self-distraction	14	5.18	1.96

The seventh specific aim of this research was the evaluation of the relationship between caregiver burden and coping strategies used by informal caregivers of cancer patients. The association between burden (as assessed using the Zarit Burden Interview) and coping strategies used (as assessed using the Brief COPE) was evaluated using the Pearson product-moment correlation. The strongest positive correlation found was between burden and self-distraction (r = .54, n = 65, p < .05), followed by the correlation between burden and venting (r = .50, n = 65, p < .05) (see Appendix H). The association between burden and self-distraction as well as venting was significant, therefore high levels of burden were correlated with high levels of self-distraction and venting.

Positive moderate correlations were found between burden and the use of emotional support (r = .47, n = 65, p < .05), self-blame (r = .46, n = 65, p < .05), humour (r = .44, n = 65, p < .05), use of instrumental support (r = .40, n = 65, p

< .05), humour (r = .38, n = 65, p < .05) and planning (r = .38, n = 65, p < .05). The aforementioned moderate correlations may be particularly indicative of moderate associations between these specific types of coping strategies used and the burden experienced by caregivers. The rest of the results pertaining to the correlations between burden and the various coping strategies are presented in Appendix H.

4.9 Correlation between distress and coping strategies used by informal caregivers

The eighth specific aim sought to investigate the relationship between distress and the coping strategies used. A correlation analysis was carried out to this end. Distress (as evaluated by using the Distress Thermometer) and coping strategies (as evaluated through the use of the Brief COPE) were evaluated using the Pearson product-moment correlation coefficient (see Appendix I). When considering the various associations between distress and the different coping strategies used, the strongest correlation was between distress and use of emotional support, r = .33, n = 65, p < .05. This was a significant and moderate relationship. Though not large in magnitude there were other statistically significant correlations found, the first was between distress and denial, r = .244, n = 65, p < .05. The second statistically significant association was between distress and venting, r = .298, n = 65, p < .05.

A standard multiple regression analysis was conducted in order to explore the relationship between distress and coping strategies. As previously mentioned the relationship between distress and various coping strategies is a critical focus of this research, therefore this analysis was carried out to elucidate this relationship further. The specific aim of the regression analysis was to explore the unique contribution, coping strategies would have in the variance of distress. Distress was therefore set as the dependant variable and the various coping strategies served as the independent variables in the computation. Thus the unique contribution of each coping strategy in explaining variance in the burden variable was evaluated (see Appendix J).

The results of the standard regression show that the R for the regression was 28.4% and eluded to equal variance in distress being explained by variance in the coping strategies used. The aforementioned was however not found to be statistically significant as can be noted in Appendix J. Though this specific research did not specifically set out to investigate directionality in terms of the predictive relationship between coping strategies used and distress, this non significant regression may provide for a noteworthy observation none the less.

4.10 Relationship between Sense of coherence and coping strategies

The ninth specific aim of the research was to explore the relationship between sense of coherence and the coping strategies used by informal caregivers. Sense of coherence was assessed by using the SOC scale, the total score of SOC was obtained by reverse scoring five of the 13 items then summing all the items together, which ranged from 15 to 82. The mean score for total SOC was 55.52, with 53.9% (n = 35) of participants falling below the mean and 45.8% (n 30) of participants having a total score of SOC which is above the mean. The three subscales of the SOC scale were also computed and as indicated in Table 4.2. The mean score for comprehensibility (19.94; SD = 6.86) was the highest among the three, which may elude to the possibility that comprehensibility as a unique dimension of SOC may be associated with informal caregiver’s ability to experience more resilience to distress. When comparing the means and standard deviations of the three dimensions, it can however be observed that the variance between them is not great, this may be due to the fact that SOC can be viewed as an over-all factor as opposed to the unidimensional perspective discussed in chapter four.

Table 4.2 Descriptive statistics for Sense of coherence subscales

Scale	Mean	Standard deviation (SD)	Minimum	Maximum	Skewness	Kurtosis
Meaningfulness	18.68	4.88	7	28	.030	-.423
Manageability	16.91	5.50	1	28	-.559	.524
Comprehensibility	19.94	6.86	5	35	.044	-.471
Total SOC (N=65)	55.52	13.36	15	82	-.184	.486

The Pearson product-moment correlation coefficient was used in order to investigate the relationship between SOC and the various coping strategies used by informal caregivers (see Appendix K). The results show that a significant moderate negative correlation between SOC and venting, r = .41 n = 65, p < .05 was found. Another significantly negative moderate association between SOC and substance use was observed, r = .36, n = 65, p <. 05. It may be inferred from these findings that high or low SOC as a resilience resource in informal caregivers may have an inverse influence on substance use and venting as coping strategies used. Coping strategies found to have a significantly weak association to SOC are denial and self-blame. The significant weak negative correlation between SOC and denial, r = .28, n = 65, p < 0.05, may indicate that high SOC is associated with lowered use of denial as a coping strategy by caregivers. The significant weak relationship between SOC and self-blame, r = .25, n = 65, p < .05, possibly points to high SOC being associated with decreased use of self-blame as a copings strategy.

The final specific aim of this research was to explore the relationship between specific demographic variables and distress experienced by informal caregivers. The two demographic variables which were looked at were patient's health and duration of care. The results show that the correlation between distress and patients health were not significant, r = .21 n = 65, p < .05. No significant relationship was found between distress and duration of care either, r = .09, n = 65, p < .05.

4.11 Summary

This chapter aimed to offer a report of all the pertinent results found in this study. The data gathered through the surveys used were analysed in order to evaluate the specific aims of this study. The distress as well as anxiety, depression and burden experienced by caregivers were explored. Further, the results of the resilience resource, sense of coherence and the coping strategies used by caregivers were presented. Lastly, the relationships between various variables under investigation were examined. The next chapter will aim to offer a discussion of the results presented in this current chapter.

CHAPTER FIVE

DISCUSSION AND CONCLUSIONS

5.1 Introduction

The theoretical and conceptual background for this research has been discussed in previous chapters. Focus will be placed throughout this current chapter on synthesizing the findings (as set out in the results chapter) of this research with the findings of previous research. An integrated discussion on the distress experienced by informal caregivers and the coping strategies they use will be presented. Depression, anxiety, caregiver burden and sense of coherence will also be considered as they relate to distress and the coping strategies used by caregivers. The limitations of the research will be examined, followed by the conclusions which can be drawn from the findings in relation to the experiences which informal caregivers of cancer patients in Namibia.

5.2 Participants characteristics

The total sample of this research included 65 adult informal caregivers, female caregivers made up 86 % of the sample and male caregivers accounted for 14% of the sample. The composition of male and female caregivers is reflective of the predominant proportion of women as caregivers (Northfield & Nebauer, 2010; Bevans et al., 2011; Dempster et al., 2011). In many cultures women assume the role of caregivers and this is true for the assumption of the role of primary caregivers when a loved one falls ill. The average age of informal caregivers was M = 37.8 which is less than the average age of the care recipient, M = 50.98, this may be due to the prevalence of cancer in individuals in middle to late adulthood in Namibia (Namibian Cancer Registry, 2009).

5.3 Demographic information

Married persons accounted for 38.5% of informal caregivers, but this was slightly less than the 41% of participants who reported being single. Both these groups of individuals may have concurrent responsibilities either with household duties or work commitments and the various roles they assume may come into conflict. Such conflicting roles may contribute to psychological strain as has been shown in literature (Demirtepe-Saygili & Bozo, 2011; Grunfeld et al., 2004; Pearlin et al., 1990). Role conflict emanating from occupational duties may be a particular challenge for informal caregivers of cancer patients as nearly half of the sample in this study reported being in full-time employment. Caring for cancer patients as previously discussed in Chapter Two, may involve helping care recipients with activities of daily living (e.g. accompanying patients to follow up hospital visits) that may conflict with their duties at work. Another source of the strain of caregiving may be financial as 55.4% of caregivers are from low to middle income households. Financial demands placed on cancer patients and their caregivers is an increasingly poignant reality for many in the face a prevailing global economic deficits which are reflected in increasing costs of health care (Lim & Zebrack, 2004). All these elements form part of primary and secondary stressors which informal caregivers have to contend with.

When characterizing the patient’s health 43.1% of caregivers indicated that care recipients experienced moderate health and 27.7% reported poor health.

Moderate to poor health of care recipients may impact caregivers' psychological well-being, this may be as a consequence of the distress and anxiety which accompanies changes in health due to illness progression. The uncertainty that underlies the often unpredictable disease trajectory of cancer may thus take its toll on informal caregivers, who as previously discussed may not have the skills to manage the disease. The unpredictable nature of the illness may also result in informal caregivers feeling a loss of control, which stress theorists have argued leads to psychological distress (Lazarus & Folkman, 1984).

The most commonly reported cancer diagnosis was breast cancer, which accounted for 23.1% of the identified cancers. This is consistent with the data presented by the Cancer Registry of Namibia (2009), where breast cancer was reported as the most prevalent cancer among women, representing 28% of all diagnoses. Colon cancer was identified as the second most prevalent cancer, with 10.8% of care recipients. A significant proportion (43.1%, f = 28) of other types of cancer diagnoses were reported caregivers reported. Kaposi Sarcoma is identified as the most commonly occurring cancer among men (19.2%) and the third most prevalent type of cancer in women (8.7%) within Namibia (Cancer Registry of Namibia, 2009). The stigma attached to Kaposi Sarcoma may have contributed to the lack of specification of the type of cancer diagnoses reported by caregivers. Informal caregivers of patients with Kaposi Sarcoma are possibly exposed to concurrent stressors as they deal with the stigma attached to HIV/AIDS as well as the concomitants of cancer.

This research aimed to investigate the general psychological distress experienced by informal caregivers as well as the coping strategies used by informal caregivers. The rest of this chapter will explore these two constructs within the Namibian context and the results of the research will be discussed as they relate to relevant concepts such as caregiver anxiety, depression, burden and sense of coherence.

5.4 Psychological distress: Its relation to anxiety and depression

5.4.1 Distress experienced by informal caregivers

The psychological distress experienced by informal caregivers was assessed using the Distress Thermometer and the results indicate that more than half (64.7%) of the sample met the criteria for distress set for this study. Zwahlen et al. (2008) set out a criterion for distress and when evaluating psychological distress, 36.9% of the sample experienced moderate distress, whereas 27.8% experienced severe distress.

The global score of the HADS has been used in previous research as a measure of distress (Mitchell, 2007) and it indicated clinically significant distress in this particular research sample. With the corroboration of the principal measure of psychological distress (DT) by the complementary measure (HADS), it may be argued that the distress experienced by informal caregivers is noteworthy. Psychological distress experienced by caregivers as has been discussed, is associated with negative patient outcomes as well as deleterious caregiver outcomes. Previous research has asserted that individuals who experience significant distress have a greater likelihood of developing psychological sequelae, such as depression and anxiety (Bevans et al., 2011; Boyer et al., 2002; Nijboer et al., 1999).

5.4.2 Anxiety and depression in informal caregivers

Anxiety experienced by caregivers was shown to be equally split between non-cases and individuals who were at or above caseness of anxiety. A definite determination of anxiety in informal caregivers cannot be made from these results, but there appears to be moderate level of anxiety in this sample. Despite the fact that the over-all mean for the sample did not meet the cut-off for anxiety, it may be argued that the variance between the mean of 7.88 versus the cut-off of 8 is a marginal difference. The correlation between distress and anxiety was found to be positively significant as well as moderate. The significant relationship between anxiety and depression can be linked to the literature which shows that psychological distress is linked to deleterious psychological affect.

Another relationship which was examined in this research was the correlation between distress and depression, which was also found to be moderate. Informal caregivers in the current sample met the cut-off score of 8 for clinically significant depression, which suggests that in comparison to anxiety, informal caregivers showed a slight tendency of experiencing more depression as than anxiety. Though not as strong as the distress-anxiety relationship both correlations are significant in a positive direction. In combination with the finding that caregivers in this study were categorized as experiencing significant distress, it may be noted that the moderate levels of anxiety and depression may change in either a positive or negative direction depending on the pattern of changes in distress.

5.5 Burden experienced by informal caregivers

The level of burden found in this sample was indicative of significant burden which has been linked to depression in informal caregivers in prior research (Haley, 2003; Schreiner, Morimoto, Arain, & Zarit, 2006). Sources of the burden experienced by caregivers was not explored in this particular research study, however there are some demographic variables which have been shown to be linked to burden experienced in caregiving which were explored in this study. These demographic variables include the patient's health, economic status and work status (Grunfeld et al., 2004). Links between burden and demographic variables cannot be made as the correlations between these variables were not examined in this particular research, therefore any discussions on this would be purely speculative for this particular group of informal caregivers.

The relationship between the psychological distress of informal caregivers and burden was explored. It is apparent that a significant moderate relationship exists between distress and burden. This direct positive correlation has been endorsed in previous studies, as the burden of caregiving has been associated with increased psychological distress (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Lowery et al., 2000, Pitceathly & Maguire, 2003). Pearlin et al. (1990) outlines the conceptual model of caregiver stress which contains burden related components of primary and secondary role strain, which were described in earlier chapters. Findings of this study relating to distress, depression and burden, reinforce the theoretical perspectives of Pearlin et al. (1990) as well as the six-element model of caregiver burden and depression (Pinquart & Sörensen, 2005).

5.6 Approaches to coping used by informal caregivers

5.6.1 Informal caregiver coping

On average the most used coping strategies among informal caregivers are acceptance, use of emotional support, religion, use of instrumental support, planning and active coping. The third chapter in this research offered a discussion on coping strategies and theoretical perspectives which highlighted the notion that coping strategies serve adaptive functions. Due to the adaptive nature of coping strategies, this research did not aim to draw definitive assertions in relation to adaptive and non-adaptive coping strategies used by caregivers, but instead sought to explore the extent to which various coping strategies were used. Literature however has shown that the various coping strategies used by individuals can be placed into categories.

The theoretical perspective of Lazarus and Folkman (1984), as previously discussed sets out two main types of coping approaches, namely; problem-focused and emotion-focused coping. Problem-focused coping is characterized by efforts to try to directly influence the actual or perceived source of the stress, whereas emotions focused coping is aimed at regulating ones unwanted emotions by using behavioural as well as cognitive efforts. Avoidant coping is an additional approach outlined by Connor-Smith et al. (2000), involves little to no effort aimed at altering the stressful situation. The coping strategies used by informal caregivers which were explored have all been shown as being associated with the three different coping approaches (Fisher, Segal, & Coolidge, 2003; Schnider, Elhai, & Gray, 2007). Problem-focused coping has been found to be related to the following strategies; active coping, planning and the use of instrumental support. Emotion-focused coping has been linked to the following coping strategies; positive reframing, humour, acceptance, religion and the use of emotional support. Other research has shown that denial, mental disengagement, behavioural disengagement, substance use, venting and self distraction are all associated with avoidant coping.

When integrating these distinct categorizations with the results of this research, a majority of the most used coping strategies by informal caregivers appear to be emotion-focused. The use of emotion-focused coping by informal caregivers is a finding which makes sense considering the fact that the literature reflects that emotion-focused coping is predominantly used in situations where individuals perceive themselves as having limited abilities in changing the stressful situation. The illness trajectory of cancer depends in part on the prognosis and treatment options available to individuals, but there are restrictions in terms of the extent to which persons are able to influence/control the eventual outcome of the illness.

5.6.2 Coping strategies and caregiver burden

Burden of caregivers and its association to coping strategies used was explored in this research. The results showed that self-distraction and venting were both strongly associated with burden. These two coping strategies are reported as being types of avoidant coping and may thus be associated with decreased adjustment. Other coping strategies were moderately correlated with burden.

5.6.3 Sense of coherence and coping strategies used

Almost half of the sample in this research had scores which fell above the mean, which shows that they had a moderate to high sense of coherence. However the other half of the sample fell below the average, which may be reflective of low sense of coherence. It could be argued that informal caregivers with low sense of coherence may experience less resilience to stressors such as the psychological strain and burden of caring for their loved one with cancer. When considering the three components of SOC, the results showed that comprehensibility was the highest dimension. Informal caregivers may tend to have a general orientation that their experiences are understandable and they are able to make sense of them on a rational level. The other dimensions of SOC did not very greatly from comprehensibility. It could therefore be suggested that on the whole, informal caregivers may perceive themselves as having the resources needed to handle the stressors they face. They may also derive meaning in their experience.

Negative moderate correlations were found between SOC and venting as well as SOC and substance use. Venting and substance as coping strategies used by informal caregivers are inversely related to SOC. Hence, high SOC might be associated with low levels of use of venting and substance use. The moderate nature of the correlation does not offer substantial support for the likelihood that this may indeed be the case.

5.7 Distress and coping strategies used by informal caregivers

A significant moderate relationship between psychological distress and emotional support was found. This positive association suggests that informal caregivers of cancer patients may use emotional support as a coping strategy when they experience increased levels of psychological distress. Use of emotional support is an emotion-focused approach to coping which is characterised with emotion regulation related to decreased distress (Chronister, & Chan, 2006). Further the use of emotional support may be argued to be related to social support which according to the Pearlin et al. (1990) model can serve as a mediator to caregiver stress.

Denial and venting have been found in previous research to be strongly associated with distress, but in this research these two coping approaches lacked considerable magnitude in their significant correlation to distress. Despite their magnitude the significance of these two approaches is consistent with findings from previous research. Venting has been reported to be associated with increased distress and it has been argued that venting does not solve problems nor does it aid in cognitive reappraisal of the stressor, but simply exacerbates negative affect (Lopez, Lopez-Arrieta, & Crespo, 2005). Denial is another avoidant coping strategy which has been reported to account for variances in distress and could be linked to increased distress (Fitzell, & Pakenham, 2010). These findings offer support for the assertion that, avoidant coping strategies do not aid in the adjustment of caregivers to their new caregiving role, but instead may worsen the psychological distress which they are likely to be experiencing.

5.8 Limitations of the study and recommendations

Though the research was aimed at investigating the distress experienced by family caregivers of cancer patients, caution should be exercised when attempting to generalize the study findings to the entire population. The convenience sample used in this research may not be representative. Despite the fact that patients from all thirteen regions make use of services at the Windhoek Central Hospital, they are not always accompanied by their family caregivers to follow-up appointments and treatment sessions. This may be due to financial restrictions or a myriad of other practical limitations. It may also be worth noting that the health care workers (i.e. nurses and administrators) were not always able to follow-up and ensure the return of questionnaires due to the work related duties which they had to attend to. The aforementioned is particularly salient when considering the fact that the questionnaires may have taken on average 35 minutes to complete. However due to the fact that the instruments were not translated into local languages the completion time may have been longer due to the variable English language proficiency of participants and this was ameliorated by allowing caregivers to take questionnaires home and return them to the researcher upon completion. Therefore some participants filled in the questionnaires at the Windhoek Central Hospital (fourth floor and Dr A. Bernard May Cancer Care Centre), and the Cancer Association of Namibia, with the assistance of the researcher, nurses and administrators, and other participants took their questionnaires home to complete them. There is some likelihood that those participants who took their questionnaires home may have misinterpreted some of the items on the questionnaires, however participants who took home questionnaires were encouraged to contact the researcher if they had any questions related to the questionnaires.

The moderate number of participants, who completed questionnaires, may have affected the sample size for the study and the statistical power of the research. Lack of statistical significance in some of the correlations which were carried out may have been affected by the moderate sample size. This could have been particularly true for the relationship between distress and the coping strategies used by caregivers.

A recommendation can be made that future research in the area of informal caregiving of cancer patients within Namibia may make use of research assistants who are proficient in several local Namibian languages in order to ensure that all participants receive personal guidance in filling out questionnaires. The second recommendation is that research instruments be translated into several Namibian languages in order to ensure that participants understand the questionnaires better and are thus able to offer the requisite response most applicable to them.

A methodological weakness in the study was the fact that the study was cross-sectional as opposed to being longitudinal. It could be argued that cancer being a chronic illness has different phases, the initial phase for instance may be categorized by the informal caregiver experiencing the shock of the diagnosis (Nijboer et al., 1999). The last phase may be characterized by the caregiver either readjusting to their loved one being in remission of cancer or grappling with the bereavement of their loved one’s terminal diagnosis or passing (i.e. death) (Nijboer et al., 1999). The differential experiences of caregivers of patients at different points in their illness trajectory may have had an influence on the results for depression and anxiety, as there were marginal variances between cases and non-cases of both depression and anxiety. A longitudinal study of cancer caregiving within the Namibian context may thus be an advantageous approach for future research.

5.9 Conclusion

With the shifts in health care from in-patient to more out-patient care, caregiving of cancer patients is increasingly falling in hands of a growing number of informal caregivers. This may be viewed as a call for an increased focus on the various outcomes for these individuals. The goal of this research was to explore the distress experienced by informal caregivers as well as the coping strategies used by individuals who assume the unexpected novel role of caring for a loved one with cancer. Consistent with previous findings this research reported significant levels of distress, which have been linked to increased likelihood of developing other deleterious psychological outcomes (Eicher & Batshaw, 1993). Depression and anxiety are the two negative outcomes which informal caregievers are prone to experience. Though this sample showed moderate levels of both depression and anxiety, there may be cause for concern as very few informal caregivers report having received any form of counselling intervention. Informal caregivers may be vulnerable to developing clinically significant depression and anxiety due to the lack of preventative mental health interventions.

Mitigating effects of internal resources such as sense of coherence and the types of coping strategies used by caregivers may buffer them from possible negative psychological outcomes (Demirtepe-Saygili, & Bozo, 2011; Griffiths, Ryan, & Foster, 2011). Informal caregivers appear to have both low and high sense of coherence, it could mean that some caregivers may have the resilience resources to cope with the psychological strain of their role, whilst others may not. Emotion-focused coping strategies were found to be used most by caregivers and though causal effects were not the specific focus of this research previous research has found that informal caregivers who engage in more emotional-coping strategies experience lowered levels of distress (Wade et al., 2001).

Use of emotional support seemed to be the coping strategy most related to distress. When considering this finding in light of the growing endorsement for cancer support groups, the argument for informal caregiver support groups could be made in order to cultivate greater emotional support amongst caregivers. This may serve to bolster the coping efforts of caregivers and ensure that they are able to use coping strategies which would serve an adaptive function for them. The later would be deemed a progressive step towards promotion of mental health amongst this group of persons who often go unrecognized, though they serve a pivotal function in the health care system as a whole.

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APPENDIX A: INFORMATION LETTER AND RESEARCH PARTICIPATION CONSENT FORM

APPENDIX B: DEMOGRAPHIC QUESTIONNAIRE

APPENDIX C: DISTRESS THERMOMETER

APPENDIX D: HOSPITAL ANXIETY AND DEPRESSION SCALE

APPENDIX E: THE BRIEF COPING WITH PROBLEMS EXPERIENCED INVENTORY

APPENDIX F: 13-ITEM SENSE OF COHERENCE QUESTIONNAIRE

APPENDIX G: THE ZARIT BURDEN INTERVIEW

APPENDIX H: PEARSON CORRELATION BETWEEN CAREGIVER BURDEN AND COPING STRATEGIES

APPENDIX I: PEARSON CORRELATION BETWEEN DISTRESS AND COPING STRATEGIES

APPENDIX J: STANDARD REGRESSION FOR COPING STRATEGIES AND DISTRESS

APPENDIX K: PEARSON CORRELATION BETWEEN SENCE OF COHERENCE AND COPING STRATEGIES

Research participant: Information Letter.

2011

Dear Participant,

I, Meunajo Tjiroze, am a registered clinical psychology master’s student at the University of Namibia. As part of my studies, I am currently conducting research on the following topic:

Distress and coping in adult family caregivers of cancer patients in Namibia.

Research indicates that many cancer patients experience psychological distress after a diagnosis of cancer. Studies have also shown that family members, particularly those taking care of the cancer patients also experience psychological distress and the burden of offering care.

The major objective of this research study is to investigate how Namibian adult family caregivers of cancer patients are affected psychologically and how they cope with caring for their loved one diagnosed with cancer. It is hoped that this investigation will impart knowledge on the nature of distress and coping mechanisms in adult family caregivers such as yourself. It is further envisioned that this knowledge may lead to improved psychosocial interventions aimed at empowering informal caregivers (like yourself), cancer clinic doctors and nurses as well as other health service professionals to employ actions and decisions benefiting the cancer patient and the family as a whole.

This letter is a friendly request to you a valued source of insight, to participate in the research project. Participation is voluntary and you will be requested to sign a consent form. Confidentiality will be maintained at all times, and participant numbers will be allocated to all participants to ensure anonymity. There are no risks involved in the research. Please take note of the fact that participation is wholly voluntary and you may choose to withdraw from participation in the research at any time.

The results of the research may be made available to you at your request. Should you agree to participate; you will be required to complete the accompanying questionnaire. It is important that you answer all the questions. Since there are no “right” or “wrong” answers, please answer all the questions as honestly as possible. Should you require any clarification regarding any questions in the questionnaires, you may ask the researcher or the research assistant. When you have completed the questionnaires in full, please give them to the research assistant, or contact me via sms at 0813098809 for the collection of the completed questionnaire.

Should you consent to partake in this research, please complete and sign the attached consent form.

Your participation is greatly valued.
Kindest regards,

Meunajo Tjiroze

Masters student

Cell no.: 081 3098809: E-mail: mtjiroze@yahoo.com

Research participation: Consent Form

Research title: Distress and Coping in adult family caregivers of cancer patients in Namibia.

I have been asked to participate in this research study and have been informed about the nature of the study. I understand the following:

- ✓ My participation in this research is voluntary, and that I may terminate my participation at any time without any repercussions on me.
- ✓ I will be required to complete all research questionnaires in full.
- ✓ Should I need any clarification about questions in the questionnaires, the researcher or research assistant will be available to provide clarification.
- ✓ All information obtained from me will be regarded with outmost confidentiality and my personal identity will not be disclosed.
- ✓ There are no physical or psychological risks involved in the study.
- ✓ I may contact Meunajo Tjiroze (081 3098809, e-mail:mtjiroze@yahoo.com), the researcher, at any time should I have any questions concerning the research.
- ✓ By agreeing to participate, I will be given a signed copy of the information letter.

By signing this consent form, I understand what my involvement in the research study means and I voluntarily agree to participate in this research.

....	....
Signature of Participant	Date
....	....
Signature of Witness	Date
(Researcher/Research Assistant)	

Participant Code…………….

*Dear participants. Please complete the following questionnaires to the best of your ability. Answer **all** questions and try to be as accurate as possible in your answers. All information will be treated with absolute **confidentiality**. **Thank you**.*

Demographic questionnaire

Age:……….. Date of birth:………….

Gender: [Male] [Female]

Home Language (Please tick one):

- ☐ English
- ☐ Afrikaans
- ☐ Damara/Nama
- ☐ Oshiwambo
- ☐ Otjiherero
- ☐ Setswana
- ☐ German
- ☐ Other(Please specify):………………….

Marital status (please tick one):

- ☐ Married
- ☐ Single
- ☐ Divorced
- ☐ Widowed
- ☐ Living with Partner

How would you describe your current work status?(Please tick one)

- ☐ Student
- ☐ Unemployed/Looking for work
- ☐ Employed full time
- ☐ Employed part time
- ☐ Self-employed
- ☐ Retired
- ☐ Other(Please specify):……………………..

How would you describe your current socio-economic status? (Please tick one)

- ☐ Low income
- ☐ Low-to-middle income
- ☐ Middle income
- ☐ Middle-to-high income
- ☐ High income

How religious/spiritual would you consider yourself to be?(Please tick one)

- ☐ Very
- ☐ Somewhat
- ☐ Not very
- ☐ Not at all
- ☐ Does not apply

Participant Code…………………

What is the highest level of education which you have completed? (Please tick one)

- ☐ No formal schooling
- ☐ Some primary schooling
- ☐ Some high school
- ☐ Grade 10/Standard 8
- ☐ Grade 12/ Standard 10
- ☐ Certificate
- ☐ Diploma
- ☐ Bachelor's Degree
- ☐ Other (Please specify):……………………………

How is the individual diagnosed with cancer related to you? (Please tick one)

- ☐ My Mother
- ☐ My Father
- ☐ My Child
- ☐ My Aunt
- ☐ My Uncle
- ☐ My Sister
- ☐ My Brother
- ☐ My Grandmother
- ☐ My Grandfather
- ☐ Other relative, e.g. neighbor, friend, family friend, cousin etc(Please specify):……………………….

How long have you been a caregiver for your loved one with cancer? ....

Indicate the age of your loved one diagnosed with cancer: ……………

When was your loved one diagnosed with cancer (Indicate month & year)?.................

Please indicate the original site of your loved one's cancer?....................

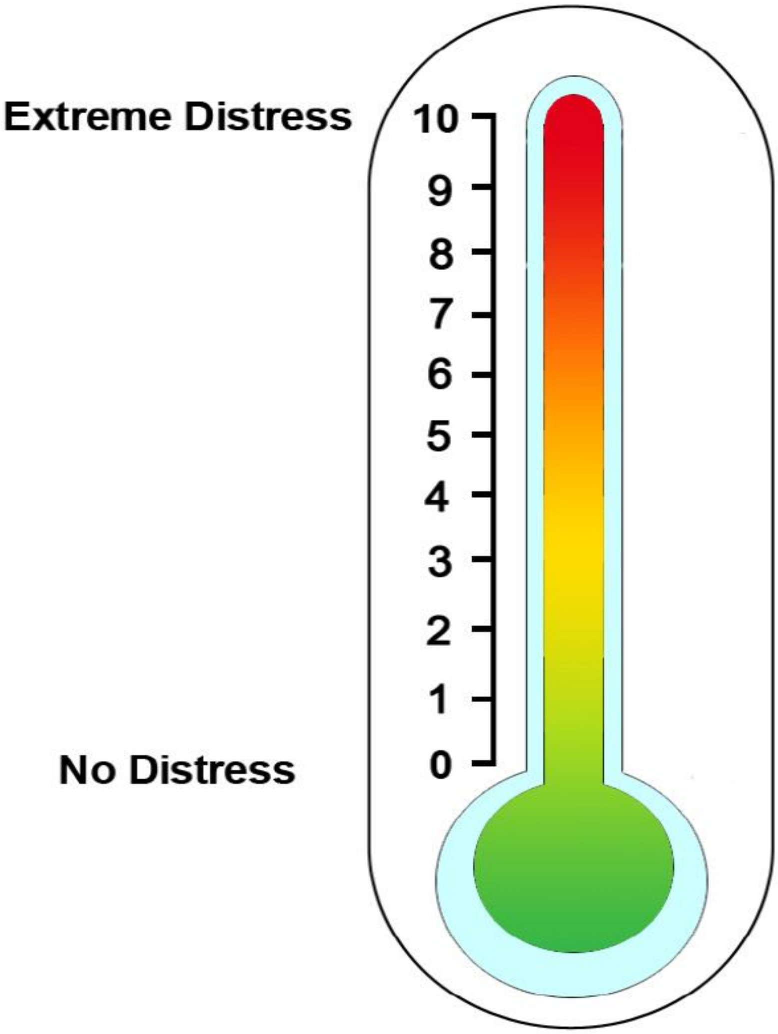
According to your own judgment, how would you describe the patient's overall physical health? (Please tick one)

- ☐ Good
- ☐ Average
- ☐ Poor

Have you received formal counseling (e.g. from social worker, psychologist, lay counselor, pastor etc) with regards to providing care to your loved one with cancer? (Please tick one)

- ☐ Yes
- ☐ No

Please circle only one number (0 – 10) that best describes how much distress you have been experiencing in the past week including today. Thank you.



HAD SCALE

Here is a series of questions relating to various aspects of your life. Each question has four possible answers. Read each item and place a firm tick (√) in the box opposite the reply that comes closest to how you have been feeling in the past week. Give only one answer to each question. Your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

		√
Most of the time………………………….	3	
A lot of the time……………………………	2	
Time to time, Occasionally……………	1	
Not at all……………………………………..	0	

I feel as if I am slowed down:

		√
Nearly all the time……………………..	3	
Very Often………………………………….	2	
Sometimes………………………………….	1	
Not at all……………………………………..	0	

I still enjoy the things I used to enjoy:

		√
Definitely as much……………………..	0	
Not quite so much………………………..	1	
Only a little……………………………….	2	
Hardly at all……………………………….	3	

I get a sort of frightened feeling like "butterflies" in the stomach:

		√
Not at all…………………………………….	0	
Occasionally……………………………….	1	
Quite often……………………………….	2	
Very often………………………………….	3	

I get a sort of frightened feeling as if something awful is about to happen:

		√
Very definitely and quite badly……	3	
Yes, but not too badly………………….	2	
A little, but it doesn't worry me…..	1	
Not at all…………………………………….	0	

I have lost interest in my appearance:

		√
Definitely………………………………………..	3	
I don't take so much care as I should………………………………………….	2	
I may not take quite as much care….	1	
I take just as much care as ever………	0	

I can laugh and see the funny side of things:

		√
As much as I always could…………….	0	
Not quite so much now………………..	1	
Definitely not so much now………….	2	
Not at all……………………………………	3	

Worrying thoughts go through my mind:

		√
A great deal of the time……………….	3	
A lot of the time…………………………..	2	
From time to time, but not too often…………………………………………	1	
Only occasionally………………………….	0	

I feel cheerful:

		√
Not at all……………………………………	3	
Not often…………………………………….	2	
Sometimes……………………………………	1	
Most of the time…………………………..	0	

I can sit at ease and feel relaxed:

		√
Definitely…………………………………….	0	
Usually…………………………………………	1	
Not Often…………………………………….	2	
Not at all……………………………………	3	

I feel restless as if I have to be on the move:

		√
Very much indeed………………………..	3	
Quite a lot…………………………………	2	
Not very much……………………………..	1	
Not at all……………………………………	0	

I look forward with enjoyment to things:

		√
As much as ever I did……………………	0	
Rather less than I used to…………….	1	
Definitely less than I used to………..	2	
Hardly at all………………………………..	3	

I get sudden feelings of panic:

		√
Very often indeed………………………..	3	
Quite often………………………………….	2	
Not very often………………………………	1	
Not at all……………………………………	0	

I can enjoy a good book or radio or TV programme:

		√
Often……………………………………………	0	
Sometimes……………………………………	1	
Not often…………………………………….	2	
Very seldom………………………………..	3	

Brief COPE

These items deal with ways you've been coping with the stress in your life since you have been caring for your loved one with cancer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Try to rate each item separately in your mind from the others. Make your answers as true **FOR YOU** as you can. After each statement**, circle the option that best describes how often you feel that way**. There are no right or wrong answers. **Please give only one answer to each question.**

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.	1	2	3	4
2. I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3. I've been saying to myself "this isn't real.".	1	2	3	4
4. I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5. I've been getting emotional support from others.	1	2	3	4
6. I've been giving up trying to deal with it.	1	2	3	4
7. I've been taking action to try to make the situation better.	1	2	3	4
8. I've been refusing to believe that it has happened.	1	2	3	4
9. I've been saying things to let my unpleasant feelings escape.	1	2	3	4

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
10. I’ve been getting help and advice from other people.	1	2	3	4
11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I’ve been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I’ve been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I’ve been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

The 13-item Sense of Coherence Questionnaire

Here is a series of questions relating to various aspects of your life. Each question has **seven** possible answers. Please tick the number, which expresses your answer, with number 1 to 7. Tick (√) the **statement** (number) which best expresses your feelings. **Please give only one answer to each question.**

Statement	1	2	3	4	5	6	7
1. Do you have the feeling that you don't really care about what goes on around you?	Very seldom or never						Very often
2. Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?	Never happened						Always happened
3. Has it happened that people whom you counted on disappointed you?	Never happened						Always happened
4. Until now your life has had:	No clear goals or purpose at all						Very clear goals and purpose
5. Do you have the feeling that you're being treated unfairly?	Very often						Very seldom or never
6. Do you have the feeling that you are in an unfamiliar situation and don't know what to do?	Very often						Very seldom or never
7. Doing the things you do every day is:	A source of deep pleasure and satisfaction						A source of pain and boredom
8. Do you have very mixed-up feeling and ideas?	Very often						Very seldom

							or never
9. Does it happen that you have feelings inside you would rather not feel?	Very often						Very seldom or never
10. Many people-even those with a strong character –sometimes feel like sad sacks(losers) in certain situations. How often have you felt this way in the past?	Never						Very often
11. When something happened, have you generally found that:	You overestimated or underestimated its importance						You saw things in the right proportion
12. How often do you have the feeling that there's little meaning in the things you do in daily life?	Very often						Very seldom or never
13. How often do you have feelings that you're not sure you can keep under control?	Very often						Very seldom or never

The Zarit Burden Interview

Instructions for caregiver: The questions below reflect how persons sometimes feel when they are taking care of another person. After each statement, **circle** the word that best describes how often you feel that way. There are no right or wrong answers. Please give only one answer to each question.

Circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite frequently	Nearly always
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Appendix H. Pearson correlation for burden and coping

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.Burden														
2.Self-distraction	.544**	-												
3.Active coping	.108	.310	-											
4.Denial	.277*	.382	.006	-										
5.Substance use	.164	.142	.098	.144	-									
6.Emotional support	.465**	.531	.301	.198	-.011	-								
7.Instrumental support	.403**	.441**	.332**	.263*	.032	.687**	-							
8.Behavioural disengagement	.257*	.359**	.195	.396**	.001	.203	.379	-						
9.Venting	.500**	.472**	.204	.451**	.049	.263*	.427**	.499**	-					
10.Positive reframing	.037	.153	-.017	.123	-.019	.216	.361**	.076	.094	-				
11.Planning	.380**	.450**	.369**	.296*	.054	.367**	.669**	.305*	.470**	.256*	-			
12.Humour	.441**	.510**	.064	.101	-.079	.222	.347**	.494**	.400**	.231	.268*	-		
13.Acceptance	.176	.195	.157	.047	.203	.134	.270*	.031	.124	.107	.414**	.137	-	
14.Religion	.249*	.265*	.075	.146	-.185	.425**	.595*	.207	.420**	.371**	.545**	.316*	.442**	-
15.Self-blame	.461**	.360**	.270*	.262*	.156	.416**	.392**	.317*	.411**	.199	.344**	.189	.135	.297*

**p < .01, two-tailed

*p < .05, two tailed

Appendix I. Pearson correlations for distress and coping strategies used by caregivers

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.Distress														
2.Self-distraction	.220	-												
3.Active coping	.127	.310*	-											
4.Denial	.244*	.382**	.006	-										
5.Substance use	.027	.142	.098	.144	-									
6.Emotional support	.325**	.531**	.301*	.198	-.011	-								
7.Instrumental support	.229	.441**	.332**	.263*	.032	.687**	-							
8.Behavioural disengagement	.097	.359**	.195	.396**	.001	.203	.379**	-						
9.Venting	.298*	.472**	.204	.451**	.049	.263*	.427**	.499**	-					
10.Positive reframing	-.163	.153	-.017	.123	-.019	.216	.361**	.076	.094	-				
11.Planning	.237	.450**	.369**	.296*	.054	.367**	.669**	.305*	.470**	.256*	-			
12.Humour	-.076	.510**	.064	.101	-.079	.222	.347**	.494**	.400**	.231	.268*	-		
13.Acceptance	.039	.195	.157	.047	.203	.134	.270*	.031	.124	.107	.414**	.137	-	
14.Religion	.156	.265*	.075	.146	-.185	.425**	.595**	.207	.420**	.371**	.545**	.316*	.442**	-
15.Self-blame	.243	.360**	.270*	.262*	.156	.416**	.392**	.317*	.411**	.199	.344**	.189	.135	.297*

**p < .01, two-tailed

*p < .05, two tailed

Appendix J. Standard regression for coping variables and distress

Variables	Distress (DV)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	B	Β	sr^2 (unique)
1.Self-distraction	.220															.052	.037	.00005
2.Active coping	.127	.310														-.085	-.054	.002
3.Denial	.244	.382	.006													.140	.094	.005
4.Substance use	.027	.142	.098	.144												-.086	-.022	.0004
5.Emotional support	.325	.531	.301	.198	-.011											.475	.288	.030
6.Instrumental support	.229	.441	.332	.263	.032	.687										-.035	-.027	.0002
7.Behavioural disengagement	.097	.359	.195	.396	.001	.203	.379									-.072	-.044	.001
8.Venting	.298	.472	.204	.451	.049	.263	.427	.499								.314	.214	.02
9.Positive	-.163	.153	-	.123	-.019	.216	.361	.076	.094							-.429	-	.05

reframing			.017														.258	
10.Planning	.237	.450	.369	.296	.054	.367	.669	.305	.470	.256						.198	.135	.007
11.Humour	-.076	.510	.064	.101	-.079	.222	.347	.494	.400	.231	.268					-.511	-.216	.02
12.Acceptance	.039	.195	.157	.047	.203	.134	.270	.031	.124	.107	.414	.137				-.049	-.038	.0009
13.Religion	.156	.265	.075	.146	-.185	.425	.595	.207	.420	.371	.545	.316	.442			.033	.027	.0002
14.Self-blame	.243	.360	.270	.262	.156	.416	.392	.317	.411	.199	.344	.189	.135	.297		.167	.082	.004
														Intercept	=	3.18		
Means	4.88	5.18	5.75	4.32	2.29	6.31	6.00	3.15	4.05	5.87	5.71	2.58	6.31	6.22	2.92		R² =	.284
Standard deviations	2.74	1.96	1.75	1.84	.701	1.66	2.10	1.67	1.87	1.65	1.87	1.16	2.10	2.30	1.35	Adjusted	R² =	.084
																	R =	.533

Appendix K. Pearson correlation SOC and coping strategies used by caregivers

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.SOC														
2.Self-distraction	-.203	-												
3.Active coping	-.095	.310*	-											
4.Denial	-.280*	.382**	.006	-										
5.Substance use	-.360**	.142	.098	.144	-									
6.Emotional support	-.140	.531	.301*	.198	-.011	-								
7.Instrumental support	-.174	.441**	.332**	.263*	.032	.687**	-							
8.Behavioural disengagement	-.224	.359**	.195	.396**	.001	.203	.379**	-						
9.Venting	-.407**	.472**	.204	.451**	.049	.263*	427**	.499**	-					
10.Positive reframing	.033	.153	-.017	.123	-.019	.216	.361**	.076	.094	-				
11.Planning	-.215	.450**	.369**	.296*	.054	.397**	.669**	.305*	.470**	.256*	-			
12.Humour	-.055	.510**	.064	.101	-.079	.222	.347**	.494**	.400**	.231	.268*	-		
13.Acceptance	-.058	.195	.157	.047	.203	.134	.270*	.031	.124	.107	.414**	.137	-	
14.Religion	.032	.265*	.075	.146	-.185	.425**	.595**	.207	.420**	.371**	.545**	.316*	.442**	-
15.Self-blame	-.252*	.360**	.270*	.262*	.156	.416**	.392**	.317*	.411**	.199	.344**	.189	.135	.297*

**p < .01, two-tailed

*p < .05, two tailed