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Predictors of cancer caregiver depression symptomatology

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Predictors of Cancer Caregiver Depression Symptomatology

By

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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College of Nursing
University of South Florida

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Dedication

I dedicate this dissertation to my partner, William D. Corbin and my parents, Henry R.

Rivera and Katherine A. Camier Rivera.

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Predictors of Cancer Caregiver Depression Symptomatology

Henry R. Rivera, Jr.

ABSTRACT

While the duration of the cancer illness may be shorter than that of other serious diseases, such as Alzheimer's disease, cancer caregivers provide many more hours of care during a week. Research directed at the intensive experience of caregiving of hospice cancer patients is needed as there is limited research of predictors of hospice cancer caregiver depression symptomatology. The purpose of the study was to examine predictors of depression symptomatology in caregivers of hospice cancer patients.

A secondary analysis was conducted using baseline assessment data of patients and caregivers from a larger study of patient/caregiver dyads from two large hospices (NIH 5R01 NR 008252). Statistical methods included Pearson's, point bi-serial, and phi correlation. Multiple regression and logistic regression were used to examine prediction. The variables of wife caregiver, patient symptom global distress, and caregiver support satisfaction accounted for 13% of the variance in caregiver depression symptomatology as measured by the CES-D 10 ($M = 2.97$, $SD = 2.15$) in the patient/caregiver dyad sample ($n = 578$). Approximately 38% of the 578 caregivers had CES-D 10 scores of 4 or greater upon patient admission to hospice. CES-D 10 scores 4 or greater have been found predictive for a diagnosis of depression (Irwin, Artin and Oxman, 1999). Examining odd ratios, wife caregiver was positively predictive and caregiver support

satisfaction was negatively predictive of CES-D 10 scores of 4 or greater. The results support the need for depression symptom screening of caregivers, the importance of support satisfaction and the need to examine additional caregiver factors, along with patient factors, that may contribute to depression symptomatology in caregivers of hospice cancer patients.

CHAPTER ONE

INTRODUCTION

Chronically ill and end of life patients are increasingly being cared for in the home by family, friends, or neighbors. These individuals are referred to as informal or voluntary caregivers. They are not professionally trained for the caregiving role and are not financially compensated. More than 44 million individuals in the United States each year are voluntary primary caregivers for a chronically ill, disabled or aged family member or friend, with the value of their services estimated at 306 billion dollars each year (Administration on Aging, 2008).

While the duration of the cancer illness may be shorter than that of other serious diseases, such as dementia, caregivers of cancer patients provide many more hours of care during a week (Haley, Lamonde, Han, Narramore, & Schonwetter, 2001).

Caregivers for end of life patients are subjected to an intense caregiving experience for which they may not have been adequately prepared or expected. Identifying caregivers at risk for depression symptomatology is particularly important in this patient population.

This is necessary not only for the physical and emotional health of the caregiver, but also that of the cancer patient whose quality of life and care may be adversely affected.

Quality of care and life is particularly critical for patients at the end of life.

While research has found a relationship between caregiving and depression, a search of the literature revealed that studies of predictors of depression symptoms in caregivers of cancer patients at the end of life are sparse. A small study of 51 caregivers

of patients with advanced cancer, recruited from ambulatory clinics, focused on caregiver sleep as a predictor of caregiver depression symptoms (Carter & Chang, 2000). There are also limited studies of caregivers of cancer patients in the hospice setting. A study comparing dementia and cancer caregivers of hospice patients had a small sample size and was limited to only spousal caregivers (Haley et al., 2001). Further research directed at the intensive experience of caregiving of hospice cancer patients and caregiver depression symptomatology is needed, due to limited research on this particular caregiving experience. There is a need to assess caregivers for depression symptoms and provide appropriate intervention. The identification of cancer caregiver depression symptomatology can be used to improve the psychological and mental health of informal caregivers, improve their quality of life and ensure quality care for those in need.

Problem Statement

The majority of studies of predictors of depression symptoms in caregivers of patients at the end of life were not of caregivers of hospice cancer patients. Many of the patient and caregiver factors that influence depression symptoms in caregivers of Alzheimer's disease and dementia caregivers may also be factors for depressive symptoms in caregivers of cancer patients. The duration of caregiving for cancer patients, however, may be shorter than that for Alzheimer's disease caregivers but more intense (Haley et al., 2001). Further research directed at the intensive experience of caregiving of hospice cancer patients and caregiver depression symptomatology is needed. There is also limited research of predictors of caregiver depression symptoms in hospice cancer caregivers. The purpose of this study was to examine caregiver and

patient factors contributing to caregiver depression symptomatology and the level of depression symptomatology in caregivers of hospice cancer patients.

Definition of Concepts

The concept of caregiver depression has not been fully defined in the literature so each word in the concept must be defined separately.

Caregiver

Caregiver is defined (Thomas, 1997, p. 320) as “one who provides care to a dependent or partially dependent person”. Caregiver is further defined for this dissertation as an informal or voluntary individual who is not professionally trained or financially compensated to render care and who provides at least four hours of care a day.

Depression Symptomatology

Depression is defined as “a mental disorder marked by altered mood” (Thomas, p. 512). The presence of at least four of the following symptoms over a two-week period, with one of the symptoms required to be either of the first two listed, may indicate depression: 1) depressed mood characterized by feelings of sadness or emptiness; 2) loss of interest or pleasure in usual activities; 3) suicidal thinking or attempts; 4) motor retardation or agitation; 5) disturbed sleep; 6) fatigue and loss of energy; 7) feelings of worthlessness or excessive guilt; 8) difficulty thinking or concentrating; or 9) changes in appetite and weight (American Psychiatric Association [APA], 2000) .

Various instruments with acceptable evidence of reliability and validity have been used to measure caregiver depressive symptomatology (Beck & Beck, 1972; Radloff, 1977; Sheikh & Yesavage, 1986). Symptoms of depression are used to make clinical diagnoses of depression. For example, depression symptoms may be further classified as

a major depressive episode or a minor depressive episode, with the classification determined by presence, the number and duration of symptoms (APA, 2000, April).

Significance of the Study

Depression symptomatology in caregivers has been described as a specific emotional reaction to the stress of caregiving (Sherwood et al. 2004). Recent studies have found 32 to 50 percent of caregivers had depressive symptoms at a level suggesting depression (Covinsky et al., 2003; Butler, Turner, Kaye, Ruffin, & Downey, 2005).

Caregiving is known to have physical and emotional effects on the caregiver (Vitaliano et al., 2002; Sherwood et al. 2004; Ferketich, Schwartzbaum, Frid, & Moeschberger, 2000). An early study comparing four-year mortality of spousal caregivers of individuals with physical problems or mental confusion found a 63% higher mortality rate in caregivers (Schulz & Beach, 1999). Caregiving has significant negative effect on cells of the immune system, including T cells and natural killer cells (Pariante et al., 1997; Scanlan, Vitaliano, Zhang, Savage, & Ochs, 2001; Vitaliano et al., 1998). In addition to effects at the cellular level, caregivers have increased levels of coronary heart disease (CHD) and metabolic syndrome when compared to noncaregivers (Vitaliano et al).

Caregiving has known physiologic effects and the frequently accompanying depression can contribute to additional physical effects. The association between high levels of depression and poor physical health has been clearly established (Ferketich et al.; Schulz & Beach, 1999; Vitaliano et al., 2002). Depression in women has been associated with a higher risk for nonfatal CHD and mortality compared to only nonfatal CHD in men (Ferketich, 2000). The physical effects of depression compound the other

deleterious effects of caregiving, particularly for those with existing physical problems. An early study of a large sample of men and women found a higher depression symptom score associated with myocardial infarction. The findings were unchanged after controlling for risk factors and signs of disease at baseline and there were no gender differences in effect sizes (Barefoot & Schroll, 1996). A recent large longitudinal study of only women, found depressive symptoms in women without baseline CHD associated with CHD mortality (Whang et al., 2009).

Depressive symptoms may include, among others, fatigue, insomnia, excessive sleep, indecisiveness and inability to concentrate, (APA, 2000). Consequently, such distress may result in the caregiver being unable to meet the caregiving needs of a multi-symptomatic cancer patient. Moreover, the physical, emotional and mental energy of the caregiving experience may overwhelm a depressed caregiver (Scanlan et al., 2001; Shultz & Beach, 1999).

Early researchers have suggested that caregiver depression symptoms may result from anticipatory grieving of losses resulting from the patient's illness as well as the eventual death of the patient. The caregiver's experience of anticipatory grief, however, does not rule out symptoms of depression (Lindemann, 1994; Walker & Pomeroy, 1996). Caregivers experiencing symptoms of depression are at higher risk for chronic depression following the death of the patient (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). Assessing individuals for depressive symptoms may help to identify individuals who are experiencing a dysfunctional grief pattern that may lead to higher levels of depression (Grassi, 2007). While anticipatory grieving may be contributory to caregiver depression symptoms, the identification of caregivers

experiencing depressive symptoms is important not only to offer further evaluation, but also to help design appropriate interventions (Haley et al., 2001).

Identifying caregiver depression symptomatology may lead to the identification of patient depression, as depression in one has been found to correlate with depression in the other (Bambauer et al., 2006; Fleming et al., 2006; Land et al., 2003). The potential for caregiver morbidity and mortality may have significant effects not only on the caregiver, but also on the quality of the care the patient receives. A longitudinal study of caregivers found caregiver depression symptoms predictive of the decision to terminate home care for the elderly and initiate placement in a nursing facility, increasing cost and removing the patient from friends, family and a familiar environment (Arai, 2001). The identification of symptoms of caregiver depression is therefore important to relieve suffering during and after the caregiver experience for the caregiver and to maintain quality of life and care for the patient.

Depression is highly treatable with most people experiencing relief of symptoms and the ability to return to their daily routines. Identifying hospice caregivers of cancer patients experiencing symptoms of depression is also important to provide for screening and early intervention. Early treatment is more effective and increases the probability of preventing recurrence (National Alliance on Mental Illness, 2006; National Institute for Mental Health, 2008). While multidisciplinary support interventions, including support groups, have been developed and are often used by cancer patients, those available to caregivers have not been developed at the same pace (McCorkle & Pasacreata, 2001; Northouse & Peters-Golden, 1993). Information supporting the effectiveness of

interventions for cancer caregivers is limited and more research is needed in order to predict those caregivers at risk (McCorkle & Pasacreta).

As previously fatal diseases, such as cancer, HIV, and heart disease, become more chronic, many individuals will require caregivers. The need will be magnified as the number of individuals over 65 increase and the mortality rate decreases. The negative effects of caregiving, including depression, may dissuade individuals from voluntarily caring for others. Unless there are willing informal caregivers, the health care system cannot financially and structurally support the needs of the increasing number of patients.

CHAPTER TWO

REVIEW OF THE LITERATURE

To examine factors contributing to caregiver depression, a review of the literature was conducted using MEDLINE (Ovid), PubMed and CINAHL search engines using keywords “caregiver”, “Alzheimer’s disease” “dementia”, “depression” “cancer”, “end of life” or “hospice” and limiting studies to informal, voluntary caregivers. Studies included were limited to English.

Depression Symptoms in Caregivers of Dementia Patients

The earliest studies of caregiving were conducted with caregivers of patients with dementia and there is a considerable amount of published research. The most common forms of the many types of dementia are Alzheimer’s disease (AD) and vascular dementia (Kukull & Ganguli, 2000; Roman, 2001). Caregiving, regardless of the patient’s disease, is known to have physical and emotional effects on the caregiver including higher mortality (Ferketich et al., 2000; Schulz & Beach, 1999; Sherwood et al. 2004; Vitaliano et al., 2002). Caregivers have increased levels of coronary heart disease (CHD), metabolic syndrome and negative effects on cells of the immune system when compared to noncaregivers (Scanlan et al., 2001; Vitaliano et al., 1998; Vitaliano et al., 2002).

There are also psychological effects of caregiving. Depression in caregivers has been described as a specific emotional reaction to the stress of caregiving with studies finding 32 to 50 percent of caregivers having depressive symptoms at a level suggesting

depression (Butler et al., 2005; Covinsky et al., 2003; Sherwood et al. 2004). Self reported rates of depression in caregivers of dementia patients have ranged from 30% to 83% (Buckwalter et al., 1999; Eisdorfer et al., 2003). Depression symptoms have been associated with physical effects on the caregiver, including decline in immunity and immune response and sleep disturbance (Castle, Wilkins, Heck, Tanzy, & Fahey, 1995; Kochar, Fredman, Stone, & Cauley, 2007; Pariante et al., 1997; Scanlan et al., 2001; Vitaliano et al., 1998). Depression symptoms in caregivers also may negatively affect the care the patient receives (Thorpe et al., 2006).

Physical and psychological factors may contribute to symptoms of depression in caregivers. Some factors are related to only the caregiver, while others are related to only the patient. These factors may also be related both the caregiver and patient.

Patient Behavioral Problems and Depression Symptoms

Behavioral problems, memory problems, and depression of AD patients have been associated with caregiver depression symptomatology and fatigue (Clark, 2002; Teri, 1997; Victoroff, Mack, & Nielson, 1998). Caregiver sleep disturbance, resulting from AD patient behavior problems, has also been correlated to increased caregiver depression symptoms (Creese, Bedard, Brazil, & Chambers, 2008).

Depression symptoms in patients have been correlated with symptoms of depression in caregivers (Bambauer et al., 2006; Fleming et al., 2006; Land et al., 2003). When patients met criteria for any psychiatric diagnosis, their caregivers were 7.9 times as likely to meet the criteria for any psychiatric diagnosis and vice versa (Bambauer et al.).

Patient Functional Status

Caregivers of terminally ill patients with high care needs, including transportation, nursing, homemaking and personal care, have higher depressive symptoms (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). Spousal caregivers' increased negative appraisal of cancer or dementia patients' ability to self-care has also been found predictive of caregiver depression symptoms (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Caregivers with no previous symptoms of depression are more likely to have depressive symptoms as the patient's need for assistance with ADL increased (Neundorfer, 2006).

Caregiver Health Status, Gender and Relationship to Patient

A caregiver's health status has been associated with caregiver depression symptoms, with caregivers reporting caregiving strain more likely to have lower levels of perceived health, greater depression symptoms, less rest, lower likelihood to rest when ill, less time to engage in exercise, and higher incidence of (CHD) than noncaregivers (Schultz et al., 1997; Vitaliano et al., 2002). The elevated incidence of metabolic syndrome significantly explained CHD prevalence in male and female caregivers (Vitaliano et al). In contrast, caregivers who report better health have lower levels of depressive symptoms (Haley et al. 2003).

There are gender differences in depression symptomatology with female caregivers, including spousal caregivers, having significantly higher levels of depression symptoms than male caregivers (Beeson, 2003; Covinsky et al., 2003; Haley et al., 2003; Thompson et al., 2004). Women have been reported to have higher rates of depression symptoms, more likely to be socially isolated and have almost twice the rate of probable

major depression (Adams, Aranda, Kemp, & Takagi, 2002; Cossette, Levesque, & Laurin, 1995; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Mui, 1995). Male caregivers may also have higher rates of depression symptoms with male gender being the most significant correlate of depression symptomatology (Siegel, Karus, Raveis, Christ, & Mesagno, 1996). Male spousal caregivers of AD patients have had depression symptoms scores significant for a diagnosis of depression (Shanks-McElroy & Strobino, 2001). The relationship of spousal caregiver has been found predictive of depression symptoms and the relationship of wife and daughter associated with higher depression symptom rates (Zanetti et al., 1998; Covinsky et al., 2003). While the studies differ, spousal caregivers, both male and female, appear to be at risk for depression symptoms.

Caregiver History of Depression

Individuals who have had a history of depression may be more likely to experience depression symptoms when assuming the role of caregiver. Caregivers of AD patients with a past depressive - anxiety disorder had a higher rate of symptoms of depression than those without a past history of those disorders (Russo, Vitaliano, Brewer, Katon, & Becker, 1995). AD patient caregivers with a prior history of depressive symptoms have also been found to have fewer depressive symptoms while caregiving (Neundorfer et al., 2006). However, ADL dependency resulted in more depressive symptoms in caregivers without a prior history of depression and in caregivers with a history of mild depressive symptoms, supporting early studies of the effect of ADL dependency on the psychological health of caregivers discussed earlier (Emanuel et al., 2000; Given et al., 1993; Haley et al. 2003; Neundorfer et al.)

Caregiver Attitude, Health, Sense of Coherence, Coping, and Neuroticism

Negative caregiver mood has been related to poor health and depression symptomatology (Billings, Folkman, Acree, & Moskowitz, 2000; Lyons, Stewart, Archbold, Carter, & Perrin, 2004). Caregivers with higher optimism were found to have significantly lower levels of depression symptoms while those with higher pessimism had significantly higher levels of depressive symptoms and poor physical health, with a faster decline in health (Lyons et al.). The higher levels of depression symptoms and poor physical health also confirm other studies linking depression symptomatology with poor health (Ferketich et al., 2000; Schulz & Beach, 1999; Vitaliano et al., 2002). Caregivers who evaluated caregiving as less stressful and had greater perceived benefits of caregiving had less depressive symptoms (Haley et al., 2003).

A caregiver's general attitude about life and ability to cope with stress has been measured using the Sense of Coherence scale (Antonovsky, 1993). Male caregivers with significantly higher sense of coherence scores had lower levels of depression symptoms (Thompson et al. 2004). Coping styles may influence depressive symptoms, with approach coping associated with lower levels of depression symptoms and avoidance coping with higher levels of depression symptoms (Haley et al., 1996). Emotion-focused coping strategies were found to mediate anxiety levels in AD caregivers but not depressive symptoms (Cooper, Katona, Orrell, & Livingston, 2008). A psycho-educational skill intervention reduced caregiver burden from patient symptoms and caregiving tasks, and increased overall quality of life. However, the study did not assess depression specifically (McMillan et al., 2006). Caregiver neuroticism, the tendency to focus on the negative aspect of caregiving, has also been associated with higher levels of

depression symptoms in a studies of dementia spousal caregivers (Gallant & Connell, 2003; Jang, Clay, Roth, Haley, & Mittelman, 2004).

Caregiver Mastery and Burden

Caregivers' perception of their competency in providing patient care is referred to as mastery (Kurt et al., 2005). Caregivers with high mastery have lower levels of depression symptomatology, with lower scores on mastery predictive of higher levels of depression symptomatology over time (Nijboer, Tempelaar, Triemstra, Van Den Bos, & Sanderman, 2001). Increased mastery has been directly associated with lower depressive symptoms (Mausbach et al., 2007).

Caregiver burden includes factors such as feelings of stress of tasks, meeting responsibilities and finances, as well as a perceived decline in health (Bedard et al., 2001; Bedard, Pedlar, Martin, Malott, & Stones, 2000). Caregiver burden is highly correlated with caregiver depression symptoms, with caregiver depression symptomatology predictive of caregiver burden (Butler et al., 2005; Lim, Sahadevan, Choo, & Anthony, 1999). Younger caregivers are more burdened than older caregivers (Brody, Litvin, Hoffman, & Kleban, 1995; Chang, Brecht, & Carter, 2001; Levesque, Ducharme, & Lachance, 1999). However, it is not possible to compare caregiver burden in non-caregivers to determine the clinical significance of burden (Weitzner, Haley, & Chen, 2000).

Caregiver Social Support

Caregivers of patients with AD and other dementias with lower social support had increased depression symptoms while those with higher levels of support had fewer symptoms (Chang, et al., 2001; Grant et al., 2006; Haley et al., 2003; Williams, 2005).

Caregiver Ethnicity

Several studies have reported differing rates of caregiver depression symptoms in various race and ethnic groups. Caucasians caregivers have been found to have more depression symptoms than African Americans caregivers (Williams, 2005). Coping and social network resources may have been responsible for the fewer depression symptoms in African American caregivers (Williams). However, no difference in Caucasian and Hispanic/Latina AD caregiver symptoms of depression has also been found (Coon et al., 2004). Anglo American, African American and Japanese American dementia caregivers have reported depressive symptom rates of 66%, 57% and 78% respectively. Mexican Americans had an 89% reported depression symptom rate clinically significant for a diagnosis of depression, of which 51% was probable major depression (Adams et al., 2002). While these rates are different, they indicate depressive symptom rates are high for all caregiver ethnicities.

Caregiver Age

Younger age has been associated with higher depression symptom levels in dementia caregivers (Butler et al., 2005; Sorensen & Pinquart, 2005). Middle-aged caregivers may be caring for a parent while raising their own children with additional family and employment responsibilities (Butler et al.; Rogerson & Kim, 2005; Sorensen & Pinquart). Dementia caregivers older than 65 years have also been found to have depression symptom levels high enough to be classified as clinically depressed (Covinsky et al. (2003). However, caregiver age has not been found predictive of caregiver depression symptoms (Butler et al.)

Depression Symptoms in Caregivers of Cancer Patients

Cancer incidence increases with age, with 76% of all cancers diagnosed in individuals 55 or older (American Cancer Society, 2008). Approximately 50% of hospice admissions are cancer patients (Connor, Tecca, Lundperson, & Teno, 2004). The emotional impact of a cancer diagnosis, coupled with a shift to outpatient treatment, has shifted the emotional and physical burden of care to caregivers outside the formal health care system (Given et al. 1993). Cancer patients are surviving longer, with those receiving intensive therapies and those at the end of life requiring the assistance of informal caregivers.

Most published caregiver studies focus on dementia caregivers, with few studies comparing the impact of caregiving on dementia and cancer patient caregivers (Haley et al., 2001). An early study comparing family dementia caregivers with cancer caregivers showed both groups had double of the rates of psychological distress than the general population but little difference between groups (Rabins, Fitting, Eastham, & Fetting, 1990). A study of dementia and cancer patients, both in the middle stages of disease, found spousal dementia caregivers experienced more negative effects of caregiving than spousal cancer caregivers. However, the researchers acknowledged that the terminal phase of the cancer patients would be more stressful and further research during the terminal phase should be conducted (Clipp & George, 1993). While the focus of research has been on caregivers of dementia patients, there is limited research on caregivers of hospice patients, including those with cancer (Haley et al.). The physical, psychological and social factors associated with depression symptomatology in dementia caregivers

may also be associated with cancer caregivers. As with dementia caregivers, the factors may be related to the patient, caregiver or both.

Patient Functional Status

Dementia caregivers provide more help with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living than cancer caregivers. Dementia caregivers are more likely to provide care in a nursing home than the cancer caregivers, however both hospice caregiver groups provide more than double the number of hours of care than caregivers of ambulatory dementia patients. While dementia caregivers provide care for many more months, cancer caregivers provide many more hours of caregiving a week. (Haley et al. 2001). Cancer patient ADL dependency, the extent to which a patient cannot perform essential activities of daily living, is correlated not only with increased patient depression symptoms, but also with caregiver depression symptoms (Given et al., 1993). Caregivers of terminally ill patients, including cancer, with high care needs including transportation, nursing, homemaking and personal care, had high depressive symptoms (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). Cancer caregivers' increased negative appraisal of the patients' ability to self-care is a predictor of caregiver depression symptoms (Haley et al., 2003).

Patient Symptom Distress and Cancer Diagnosis

There are symptom differences between cancer patients and dementia patients. While there were no significant differences in the occurrence of memory or disruptive behaviors between both groups of patients, cancer patients had more depressive behavior and higher levels of pain, appetite loss and constipation while dementia patients had more confusion (Haley et al., 2001). Patient behavior problems were associated with higher

caregiver depression symptomatology in both caregiver groups (Haley, et al., 2003). Symptom distress in cancer patients has been correlated with depression symptoms in their caregivers (Given et al., 1993; Kurtz et al., 1995; Kurtz, Kurtz, Stommel, Given, & Given, 2001; Redeker, Lev, & Ruggiero, 2000; Bambauer et al., 2006; Fleming et al., 2006).

Patient Quality of Life and Depressive Symptoms

Patient symptom distress had been negatively correlated with patient quality of life (McMillan & Small, 2002). Patient quality of life may therefore impact caregiver depression. Specific cancer diagnosis may also be associated with higher caregiver depression symptoms. Studies of gastrointestinal and lung cancer patients have found significant levels of caregiver depression symptoms (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Haley et al., 2001).

Depression symptom level in cancer patients has been correlated with caregiver depression symptom level (Fleming et al., 2006). When advanced cancer patients met the criteria for any psychiatric diagnosis, their caregivers were 7.9 times as likely to meet the criteria for any psychiatric diagnosis and vice versa (Bambauer et al., 2006).

Caregiver Social Support

Greater satisfaction with social support was also associated with higher life satisfaction (Haley, et al., 2003). Cancer caregivers reporting a low level of social support have more depression symptoms over time than those who reported a high amount of social support (Nijboer et al., 2001). Other studies have also confirmed that a lack of perceived social support contributes to caregiver depression symptoms (Chang et al., 2001; Miller et al., 2001).

Caregiver Relationship to Patient, Sense of Coherence and Burden

Over 50% of the hospice spousal dementia caregivers and spousal cancer caregivers have been found to have clinically significant symptoms of depression and depression rates three times that of the general population. Women caregivers had more depressive symptoms and higher depressive levels than male caregivers. Both caregiver groups also had significantly lower life satisfaction and poorer physical health (Haley et al. 2001). Sense of coherence and caregiver burden have been associated with caregiver depression symptomology in end life cancer patient caregivers (Grosv, Fossa, Sorebo, & Dahl, 2006; Tzuh Tang & Li, 2008).

Caregiver Health Status, Sleep Disturbance, and Gender

Both cancer and dementia caregivers reporting better health have lower levels of depressive symptoms and higher life satisfaction (Haley, et al., 2003). Lower health status in caregivers of end of life cancer patients in community settings, though not including hospice, has been associated with caregiver depression symptomology (Doorenbos et al., 2007). Sleep problems in caregivers of advanced cancer patients predicted 63.6% of caregiver depression symptoms (Carter & Chang, 2000). Regarding gender, female caregivers have been found to have higher level of depression symptomology than male caregivers (Covinsky et al., 2003; Haley et al., 2003; Thompson et al., 2004). Male caregivers have also been significantly associated with caregiver depression, suggesting both genders are at risk for depression symptomatology (Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2007).

Caregiver Mastery and Neuroticism

Cancer caregivers with high mastery had lower levels of depression symptomology with lower scores on mastery predictive of higher levels of depression symptomology over time (Nijboer et al., 2001). Caregiver neuroticism has also been associated with caregiver depression symptomatology in cancer patients (Carter & Acton, 2006; Kim, Duberstein, Sorensen, & Larson, 2005).

Theoretical Framework

The Framework of a Good Death (Emanuel & Emanuel, 1998) model includes four components: 1) fixed characteristics of the patient (age, ethnicity); 2) modifiable dimensions of the patient's experience (symptoms, social support); 3) potential interventions provided to patients, families, friends, healthcare providers, and others, and 4) outcomes. Emanuel, Alpert, Baldwin, and Emanuel (2000) assessed the validity and stability of the model over time, reporting good construct validity of the tested portion of the model, with eight variables accounting for 46% of the variance in the patient's end of life experience (Cronbach's α 0.63 to 0.85). The model was adapted to clarify the flow of the model from left to right, include caregivers and include measurable outcomes. The modified model served as the framework for the original study (R01 NR008252) and this secondary analysis (Figure 1). This secondary analysis utilizes baseline data resulting from the original study's structured assessment.

Model

The major factors from the literature associated with caregiver depression symptomatology were used to construct a model from the McMillan's modified Emanuel and Emanuel (1998) Model of a Peaceful Death to predict hospice cancer caregiver

depression symptoms (Figure 2). Caregiver and patient fixed physical and psychosocial factors combine with caregiver and patient modifiable physical and psychosocial factors in predicting caregiver depression symptoms. The patient’s cancer diagnosis and the caregiver’s gender, ethnicity, age, health status, previous history of depressive symptoms, and a relationship to patient are immutable at the start of the caregiving experience. Modifiable factors which may vary to influence caregiver depression symptoms either positively or negatively are: patient’s symptom distress, functional status, depression symptoms, and quality of life and the caregiver’s perception of social support, mastery of patient care, burden, coping skills, attitude and sense of coherence.

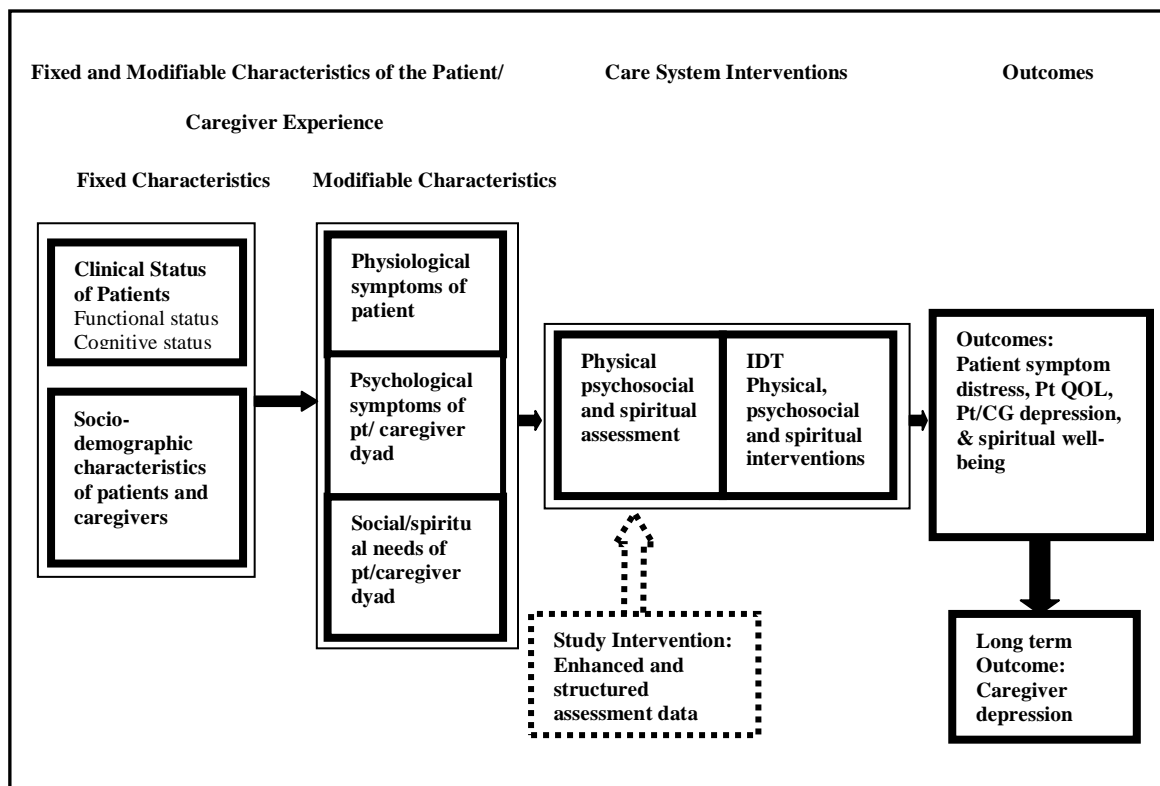


Figure 1. McMillan’s Modified Emanuel and Emanuel (1998) Model for a Peaceful Death

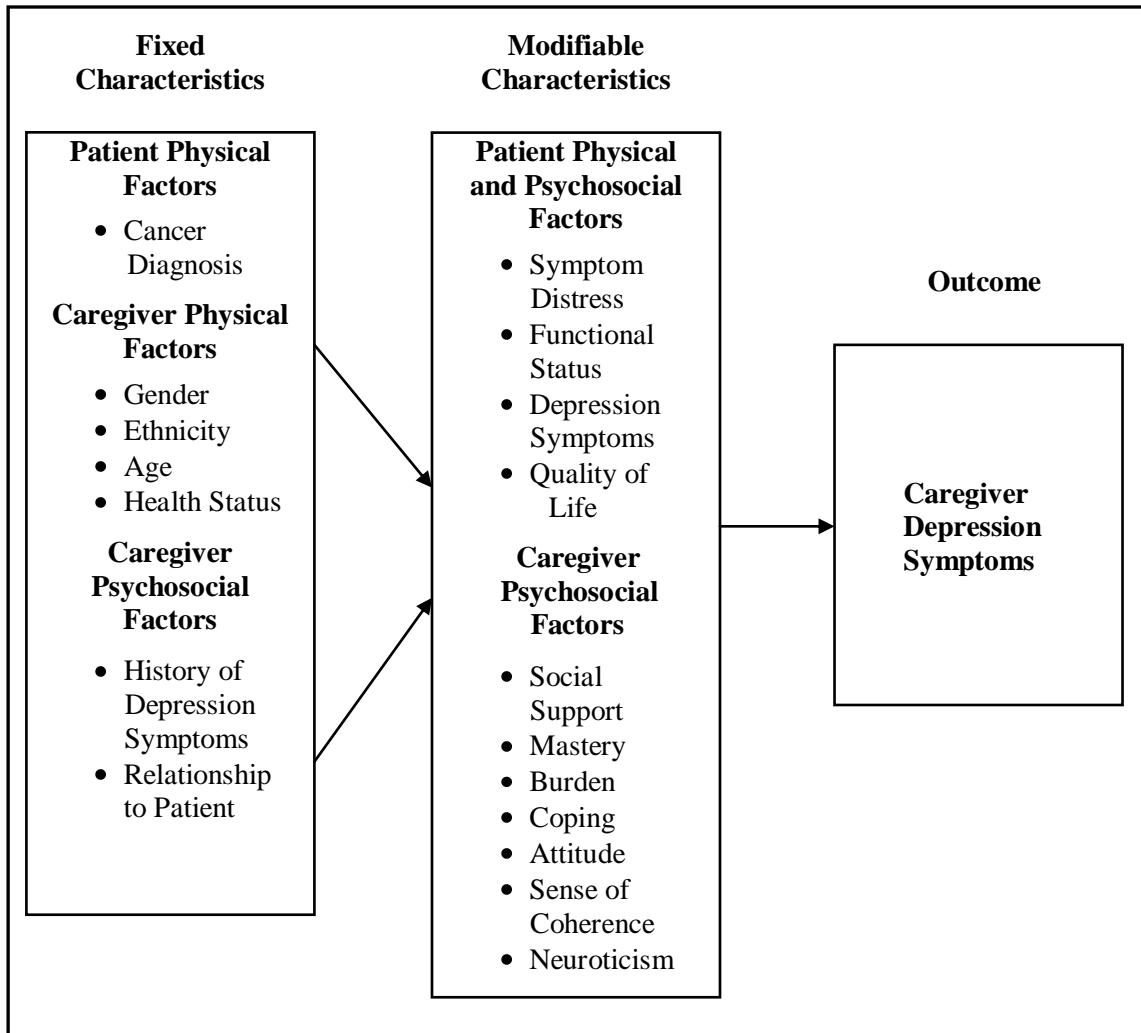


Figure 2. Prediction of Caregiver Depression Symptomatology from McMillan's Modified Emanuel and Emanuel (1998) Theoretical Model of a Peaceful Death

The major factors associated with caregiver depression symptoms, available from baseline assessment data from the original study, were used to construct a model for the current study to predict hospice cancer caregiver depression symptoms (Figure 3). The available physical and psychosocial patient factors were cancer diagnosis, symptom distress, functional status, depression symptoms and quality of life. The available caregiver physical and psychosocial factors were gender, ethnicity, age, health status, relationship to patient and social support. Caregiver history of depression, mastery,

burden, coping, attitude, sense of coherence, and neuroticism were not measured in the original study and are represented in the boxes with dotted lines.

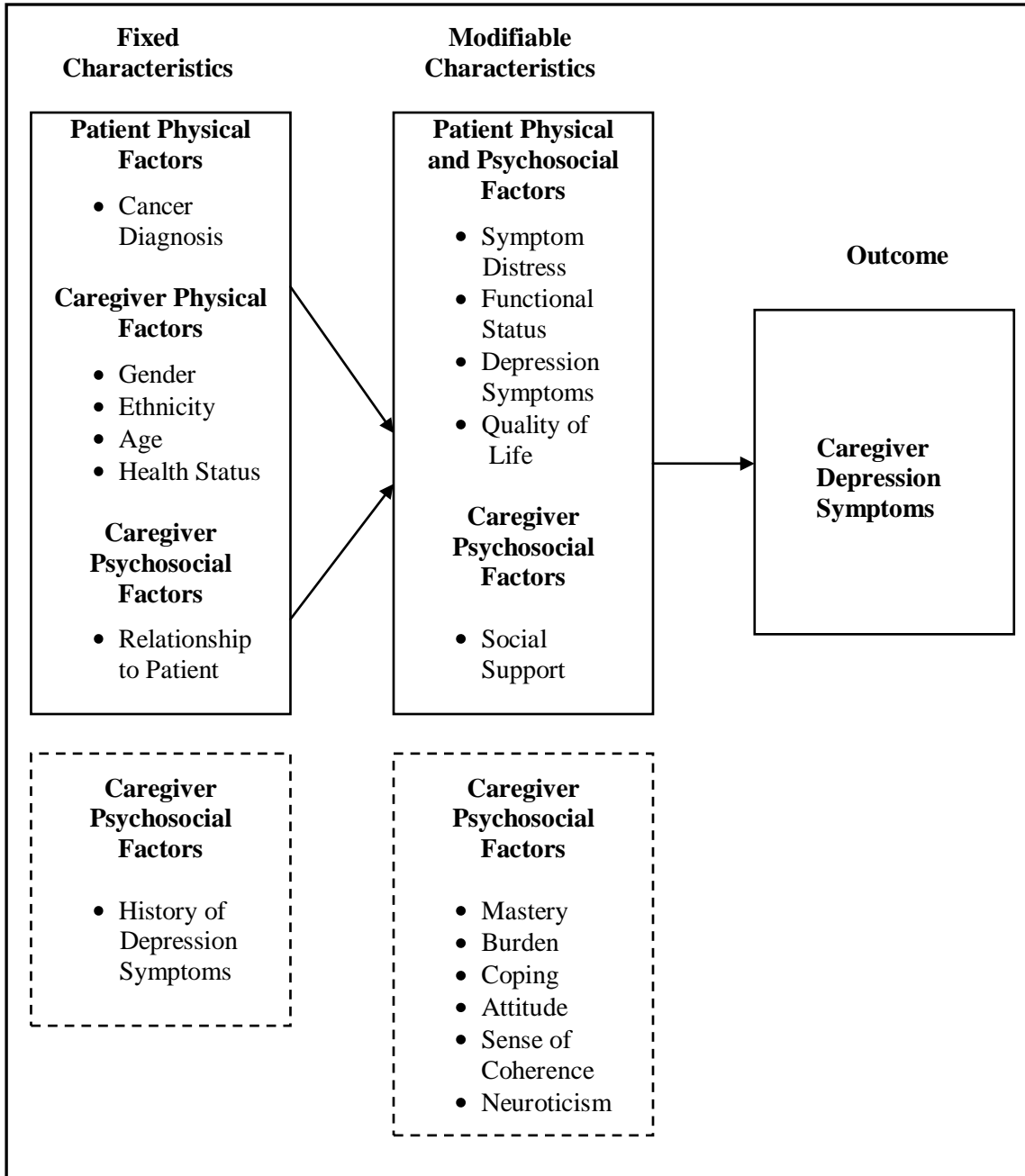


Figure 3. Prediction of Caregiver Depression Symptomatology without Caregiver History of Depression, Mastery, Burden, Coping, Attitude, Sense of Coherence and Neuroticism

Research Question and Hypotheses

The Prediction of Caregiver Depression Symptomatology from McMillan's Modified Emanuel and Emanuel (1998) Model of a Peaceful Death from the Systematic Assessment to Improve Hospice Outcomes Study (Figure 3) was used in this study to address the following:

Question

What is the level of depressive symptoms in hospice cancer caregivers?

Hypothesis 1

The patient and caregiver factors in the model are correlated with caregiver depression symptomatology.

Hypothesis 2

The patient and caregiver factors in the model are predictive of caregiver depression symptomatology.

Hypothesis 3

The patient and caregiver factors in the model are predictive of caregiver depression symptom scores of 4 or greater.

CHAPTER THREE

METHODS

Chapter three presents the methodology used in this study. Included are the institutional approval, design, model, instrumentation, and procedures.

Institutional Approval

The original study, “Systematic Assessment to Improve Hospice Outcomes” (NIH 5R01 NR 008252), was approved by participating hospices and USF Institutional Review Board for the Protection of Human Subjects. This secondary analysis of non-identifiable data was determined by USF Institutional Review Board approval not to require additional approval.

Design

A secondary analysis of baseline data set from a current study analyzes available factors from a large sample of caregiver and patient dyads to examine predictors of depression symptoms in caregivers of hospice cancer patients. The study used the data set from the larger study “Systematic Assessment to Improve Hospice Outcomes.” (NIH 5R01 NR 008252). The study sample of patient/caregiver dyads was drawn from two large hospices that are partners in the *Center for Hospice, Palliative Care and End of Life Studies at the University of South Florida*. Caregiver inclusion criteria was (1) at least 18 years old and (2) identified as a primary caregiver for a hospice cancer patient providing care for at least four hours a day. Caregivers were excluded if they were in active treatment for cancer. Patient inclusion criteria was (1) cancer diagnosis, (2) score of 8 or

higher on the 10-point Short Portable Mental Status Questionnaire (MacNeil & Lichtenberg, 1999), score of 40 or higher on the Palliative Performance Scale (Anderson, Downing, Hill, Casorso, & Lerch, 1996) and (4) able to read and write English. Patients were excluded if they were confused, excessively debilitated, comatose or actively dying. Patients and caregivers who meet study criteria were approached within 24-72 hours of admission to hospice. Caregivers from multiple hospice teams with equivalent patient profiles were identified and post-hoc analysis was conducted to ensure team equivalency.

Instruments

Caregiver Variables

Gender, Ethnicity, Age and Relationship to Patient

Standard demographic information was collected from caregivers via self-report in a semi-structured interview. Included were caregiver gender, ethnicity, age and relationship to the patient.

Health Status

The SF-12 is a short survey of 12 questions selected from the SF-36 Health Survey combined to create physical and mental function scales to assess physical and mental health. Physical and Mental Health Composite Scores are calculated for the 12 combined and weighted questions using scoring algorithms, with scores ranging from 0 to 100, with 0 indicating the lowest level of health and 100 the highest level for both scales. The SF-12 developers reported strong test-retest reliability for the physical and mental correlation of .89 and .76 (n = 232) respectively. Validity of the physical component (r = .90) and mental component (r = .93) with the original scale was high (Ware, Kosinski, & Keller,

1996). A more recent study found the scale valid and reliable for use in older adults (Resnick & Nahm, 2001).

Social Support

Social support as perceived by caregivers was assessed using a subscales of an 18-item, multidimensional measure from the work of Krause and Borawski-Clark (1995). The support satisfaction scales have been used in studies of hospice caregivers and older adults in the community (Haley et al., 2003; Jang, Haley, Small, & Mortimer, 2002; Jang, Mortimer, Haley, Chisolm, & Graves, 2002). The self-report summated rating scale has total scale scores ranging from 18 (lowest support) to 72 (highest support) with items 15-18 reverse scored. Support satisfaction scales include physical support, such as assistance with housework, shopping and transportation (3 items, $\alpha = .72$), emotional support, such as interest, concern and comfort from others (4 items, $\alpha = .83$), and informational support, such as sharing information and similar experiences from others (4 items, $\alpha = .77$). The study used a three question physical, emotional and informational support satisfaction scale with a possible range of total scores of 1 to 12. Social support has been found to be predictive of depression in hospice caregivers (Haley et al.).

Patient Variables

Cancer Diagnosis

Standard demographic information was collected from the patients via self-report in a semi-structured interview and patient record. Included was a cancer diagnosis.

Symptom Distress

The Memorial Symptom Assessment Scale (MSAS) was designed to assess symptoms associated with cancer by severity, frequency of occurrence and the distress it

produces using 33 items. Items in the subscales of intensity and distress of occurring symptoms are scored from 0 to 4, with higher scores indicating more intense or distressing the symptom is for the patient. The validity and reliability of the original instrument for the Total Prevalence, Psychological and Physical Subscales were strong (alpha = .83-.92) when used with individuals receiving active cancer therapy (Portenoy et al., 1994). A shortened version was used for the original study using 25 symptoms instead of the 33 found in the original MSAS, with symptoms linked to cancer therapy removed to decrease patient burden. The revised scale, used in an earlier study, found correlation between MSAS distress scores and the Hospice Quality of Life Index scores were moderately strong and negative ($r = -.72$; $p < .001$) providing further support for construct validity of the MSAS for use with end of life cancer patients. The reliability of the intensity and distress scores were good ($r = .73-.74$) using coefficient alpha (McMillan & Small, 2002). In the current study, only the symptom distress subscale score was used as a measure of patient symptom global distress.

Functional Status

Activities of Daily Living Index (ADLI). The ADLI assesses six activities of daily living; bathing, dressing, toileting, transfer, continence, and feeding (Katz et al, 1963). The ADLI was used to interview patients to their abilities to perform daily activities. The patient interview was conducted to relieve the burden to patients and allow for completion of the Palliative Performance Scale.

Palliative Performance Scale (PPS). The PPS was used to assess the physical condition and functional status of persons receiving palliative care. The instrument measures three broad areas: mobility, intake and level of consciousness in five categories

(degree of ambulation; ability to do activities and extent of disease; ability to do self-care; food/fluid intake; and state of consciousness. The PPS is scored from 0-100% at 10% increments with higher scores reflecting higher functional status. The developers of the scale assessed validity by comparing length of survival with the PPS score of 129 patients on admission to a hospice unit. The average time until death in days was 1.8 for scores of 10%, 2.62 for 20%, 6.7 for 30%, 10.3 for 40%, 13.87 and only 2 patients for 60% or higher (Anderson et al, 1996). Reliability statistics were not reported by the original developers of the scale. However a recent study of 466 patients enrolled in hospice found PPS score was a strong independent predictor of mortality ($p < 0.001$) with six month mortality rates at 96% for scores 10–20, 89% for 30–40, and 81% for ≥ 50 (Harrold et al., 2005). The authors of the original study for this secondary analysis assessed validity and reliability of the PPS finding strong positive correlations between the PPS and Karnofsky Performance Status ($r = .88$ -.97, $n = 23$) supporting construct validity and very strong inter-rater reliability ($r = .95$) between two raters (McMillan et al., 2001).

Depression Symptoms

The 10-item version of the Clinical Epidemiological Scale-Depression (CES-D) (Radloff, 1977), referred to as the “Boston short form”, was used to measure symptoms of depression. Items are scored as either present or absent, rather than rated for frequency as with the full CES-D, with higher scores representing more depressive symptoms. Psychometric characteristics of this short form (CES-D 10) showed that Cronbach’s alpha was .92 and test-retest reliability was .83, indicative of excellent reliability. Correlation of the short form and full CES-D was .88, suggesting that the short form is highly correlated with the lengthier and more widely validated full version.

A cutoff of 4 or more on the scale was found to have high sensitivity (97%), specificity (84%), and positive predictive value (85%) in comparison to clinical diagnosis of depression using the SCID, indicating excellent validity for the scale (Irwin, Artin and Oxman, 1999). Therefore scores of four or higher on the CES-D 10 are clinically significant for a diagnosis of depression. The CES-D 10 scale is well suited for assessment of depressive symptoms in cancer patients and their caregivers who may be burdened by the longer version.

Quality of Life

The Hospice Quality of Life Index-14 (HQLI-14) was used and is a shortened version of the previously used and validated Hospice Quality of Life Index (McMillan & Weitzner, 1998). The shortened version (HQLI-14) is designed for repeated clinical use with hospice patients and includes three aspects of overall quality of life: Psycho-physiological well-being; Functional well-being; and Social/spiritual well-being. Each item is scored on a 0 to 10 scale with 10 being the most favorable response; item scores are added to obtain a total scale score. Total scores can range from 0 (worst quality of life) to 140 (best quality of life). Correlations with the original HQLI subscales Psychophysiological ($r = .90, p = .000$) Functional ($r = .96, p = .000$), and Social/spiritual well-being ($r = .89, p = .000$), as well as total score ($r = .94, p = .000$), were very strong and provide evidence of validity of the shortened scale. Cronbach's alpha for the subscales of the short form subscales Psycho-physiological ($r = .68$), Functional ($r = .72$), and Social/spiritual ($r = .82$) well being and total score ($r = .77$) were acceptable and expected for the shortened scale (McMillan et al., 2001).

Caregiver Dependent Variable

Depression Symptoms

The 10-item version of the CES-D (Radloff, 1977), as described previously, was used to measure caregiver depression symptoms. As previously discussed, the CES-D 10 scale is well suited for assessment of depressive symptoms in cancer patients and their caregivers.

Data Analysis Procedures

Demographic data from caregivers and patients was reported using frequencies, percentages, means and standard deviations. Pearson's, point bi-serial and phi correlations were used to examine relationships between caregiver depression symptoms and the patient and caregiver variables. Multiple regression analysis was used to examine whether caregiver health status, gender, ethnicity, age, relationship to patient, social support and patient symptom global distress, functional status, depression symptoms, and quality of life were predictive of CES-D 10 score. Logistic regression analysis was used to examine whether these variables were predictive of CES-D 10 scores of 4 or greater. Early research determined, using a cutoff of 4 or more on the CES-D 10 scale, sensitivity, specificity, and positive predictive value of the scale were 97%, 84%, and 85%, respectively, when compared with clinical diagnosis of depression using the SCID. Therefore, scores of 4 or higher on the CES-D short form are clinically predictive for a diagnosis of depression (Irwin et al., 1999). Statistical significance was defined as $p < 0.05$ and the analysis was conducted using SAS 9.1 (SAS Institute Inc., Cary, NC).

CHAPTER FOUR

RESULTS

Chapter four presents the results of the data analysis. Included are preliminary analysis, descriptive statistics, variable correlations, multiple regression analysis, and logistic regression analysis.

Preliminary Analysis

The sample of caregivers and patients was analyzed by univariate and frequency analysis. Means and standard deviations were reasonable. The original sample size was 719 patient/caregiver dyads. Missing, no response, and erroneous data entry resulted in the removal of 141 patient/caregiver dyads.

Descriptive Statistics

Sample Characteristics

The sample consisted of 578 cancer patient/caregiver dyads newly admitted to hospice home care, for a total of 1156 individuals. Most caregivers were women, Caucasian, and lived in suburban areas, were age 65, and in below average physical and mental health. More than half reported they were patient spouses (Table 1).

Patient Variables

Cancer Diagnosis

Lung /Mesothelioma, pancreas, colorectal, prostate, and breast were the most frequent diagnoses. These five accounted for 63.1% of patients.

Table 1

Demographic Characteristics (n = 578)

Variable	Mean	Std Dev	Frequency
Patient			
Quality of Life	102.39	17.12	
Functional Status	57.99	10.98	
Symptom Distress	20.99	13.89	
Depression Symptoms	2.93	2.15	
Cancer Diagnosis			
Lung/Mesothelioma			208
Pancreas			50
Colorectal			40
Prostate			33
Breast			33
Caregiver			
Age	64.95	14.01	
Phys. Health	30.16	7.75	
Men. Health	24.37	8.02	
Social Support	10.86	1.67	
Depression Symptoms	2.97	2.15	
Gender			
Female			426
Male			152
Ethnicity			
Caucasian			554
Non-Caucasian			24
Relationship to Patient			
Wife			245
Husband			101
Daughter			86
Other			146

Symptom Distress

Patient symptom global distress score totals ranged from 0 to 78 out of a possible range of 0 to 100. Lack of energy and pain were among the most frequently occurring symptoms and those with the highest symptom global distress (Table 2). The mean number of symptoms per patient was 10 each.

Table 2

Patient Symptom Frequency and Percent with Mean and Standard Deviation of Symptom Distress

Symptom	Frequency	%	Mean	SD
Lack of energy	503	87.0	2.61	1.22
Pain	409	70.8	2.29	1.16
Dry mouth	404	69.9	1.84	1.26
Shortness of breath	348	60.2	2.22	1.27
Lack of appetite	345	59.9	1.90	1.35
Feeling drowsy	341	59.0	1.44	1.27
Constipation	266	46.0	2.45	1.28
Cough	264	45.7	1.70	1.26
Worrying	250	43.3	2.10	1.29
Feeling sad	245	42.4	2.08	1.12
Difficulty sleeping	242	41.9	2.35	1.15
Nausea	182	31.5	2.11	1.18
Feeling bloated	161	27.8	2.25	1.24
Difficulty swallowing	160	27.7	2.26	1.14
Problems with urination	143	24.7	2.22	1.11
Vomiting	93	16.1	2.35	1.31
Diarrhea	90	15.6	2.44	1.27
Sexual problems	82	14.2	2.59	1.31

Functional Status

Patient Palliative Performance Scale scores ranged from 40 to 100 out of a possible range of 0 to 100. Most scores were in the 50-70 range, indicating a moderate functional status.

Depression Symptoms

Patient CES-D 10 depression symptom scores ranged from 0 to 9 out of a possible range of 0 to 10. The percentage of caregivers reporting no depression symptoms was 12.8%, 49.3% reported scores of 1 to 3 and 37.9% reported scores of 4 or greater.

Quality of Life

Patient HQLI-14 scores ranged from 52 to 140 out of a possible range of 0 (worst quality of life) to 140 (best quality of life). Single question scores have a possible range of 0 to 10. Mean scores on single questions ranged from a high of 9.46 on satisfaction with physical care to a low of 5.40 on enjoyable activity (Table 3).

Table 3

Quality of Life Question Mean and Standard Deviation

Questions	Mean	SD
How satisfied are you with the physical care?	9.46	1.16
How satisfied are you with emotional support?	9.27	1.35
Do surroundings improve sense of well-being?	9.00	1.63
How satisfied with relationship with God?	8.64	2.20
If you experience pain, how completely is it relieved?	8.42	2.12
How sad do you feel?	7.45	2.77
How satisfied with your ability to concentrate?	7.08	2.75
How well do you sleep?	6.75	2.58
How breathless do you feel?	6.73	2.92
How constipated are you?	6.70	3.39
How satisfied with your level of independence?	5.98	3.43
How worried about your family and friends?	5.73	3.30
How well do you eat?	5.51	3.37
How much enjoyable activity do you have?	5.40	3.09

Caregiver Variables

Gender

Females comprised 73.8% of the caregivers. Males accounted for 26.2%.

Ethnicity

Caucasian caregivers comprised 95.8% of the sample. Non-Caucasian caregivers account for only 4.15% of the sample.

Relationship to Patient

The majority of caregivers identified their relationship to the patient as wife 42.4%, husband 17.5%, and other 25.2%. Daughters accounted for 14.9%.

Age

The caregiver age ranged from 19 to 97 years. Caregivers aged 46 to 64 years accounted for 36.9%. Those age 65 or over, comprised 54.1% of caregivers.

Health Status

The Physical Health Composite (PCS) indicated below average physical health. The Mental Health Composite (MCS) indicated below average mental health.

Social Support

Caregiver physical, emotional and information support satisfaction scores ranged from 3 to 12, out of a possible range of scores on the scales of 0 to 12. The percentage of caregivers scoring 9 or above on the 12 point scale was 90.8%.

Depression Symptoms

Caregiver depression symptom scores ranged from 0 to 10, out of a possible range of scores on the scale of 0 to 10. The percentage of caregivers reporting no depression symptoms was 12.6%. The percentage of caregivers reporting depression symptom scores of 1 to 3 was 49.9% with 37.5% reporting scores of 4 or greater. The mean caregiver depression symptom score for females was somewhat higher and the standard deviation was somewhat smaller. In the sample, 38.3% of females reported depression symptom scores of 4 or greater compared to 35.5% of males with scores of 4 or greater.

Summary

All patient and caregiver contiguous variables demonstrated acceptable normal ranges of skewness ($SK > -1.0$ and < 1.0) and kurtosis ($KU > -2.0$ and < 2.0). The kurtosis for the caregiver social support satisfaction variable, while outside the normal range, was not extreme enough to be considered unacceptable for analysis.

Multiple Regression

Correlation with Caregiver Depression Symptoms

The variable for caregiver ethnicity was dichotomized with a code of 0 for non-Caucasians and a code of 1 for Caucasians. Dichotomized variables codes of 0 and 1 were used for the categorical variables of caregiver relationship to patient and patient diagnoses. The relationships among the variables were analyzed using Pearson product moment and point bi-serial correlations (Glass & Hopkins, 1996).

The analysis resulted in six variables with significant correlations with caregiver depression symptoms (Table 4). Patient symptom global distress, patient QOL, wife caregiver, other caregiver, and caregiver ethnicity had low, positive, significant correlation with caregiver depression symptoms. Caregiver support satisfaction had a moderate, negative, significant relationship with caregiver depression symptoms. Significant negative correlations between the categorical variables of wife and other caregiver relationship to patient were expected as they are mutually exclusive. The intercorrelation between patient MSAS and HQLI-14, reported in earlier studies, was also expected. None of the intercorrelations among variables were sufficient to be redundant in predicting the dependent variable, caregiver depression symptoms.

Table 4

Patient and Caregiver Variable Intercorrelations

	CESD-10 D	Sx Dist	QOL	Wife	Other	Ethnicity	Supp.
CES-D 10	1.000						
Sx Dist	.095 .021	1.000					
QOL	.083 .045	-.643 <.000	1.000				
Wife	.095 .022	-.016 .705	-.011 .794	1.000			
Other	-.115 .005	.008 .851	-.035 .403	-.499 <.000	1.000		
Ethnicity	-.087 .035	.017 .675	-.107 .010	-.050 .233	.001 .972	1.00	
Supp.	-.327 <.000	-.034 .403	.061 .142	.074 .076	-.010 .817	.060 .149	1.000

Note: CES-D 10 = caregiver CES-D 10, Sx Dist. = MSAS, QOL = HQLI-14, Wife, Other = caregiver relationship to patient, Supp = patient support satisfaction. Significant correlations are captured in bold.

Multiple Regression Analysis

The variables correlated with caregiver depression symptoms were entered or removed individually into the regression as predictor variables, based on the prediction model developed from the literature and significance of the squared semi-partial correlation coefficients, (Hays, 1994). The resulting regression model included wife caregiver, patient global symptom distress, and caregiver support satisfaction as predictor variables, with caregiver CES-D 10 score as the dependent variable (n = 578). The results suggest the linear combination of the variables accounted for approximately 13% of the variance in caregiver CES-D 10 score ($R^2 = .1290$) (Table 5). The significance test for this R^2 was $F(3, 574)$, root mean square = 67.58807, $p < .0001$, therefore the model was significant.

The squared semi-partial correlation coefficients for all variables were all significant at the $p < .05$ level suggesting the variables sufficiently contribute to the variance in CES-D 10 score. Cohen's (1992) effect size ($f^2 = R^2 / (1-R^2)$) was computed to be .15, which can be interpreted as medium using Cohen's rough guidelines (.02 small, .15 medium, .25 large). The root mean square error was 2.01010 indicating the predictions for caregiver CES-D 10 score were off by about 2.01. The obtained linear equation, with the standardized regression coefficients that determine the contribution of each predictor to caregiver symptom total score, was: Caregiver CES-D 10 = 7.1365 + 0.5264 * wife caregiver + 0.0132 * patient symptom global distress – 0.4296 * caregiver support satisfaction.

Squared semi-partial correlations obtained for each predictor indicate the six variables accounted for 13% suggesting that almost none of the variance in caregiver depression symptom total score was in common to the multiple predictors. The data was screened for outliers and possible violation of the assumptions underlying regression. The maximum student residual was 3.407 and Cook's D was 0.013, therefore, none of the cases had an undue influence on the regression analysis. The scatterplot of the residual with predicted values revealed no violations of linearity or homoscedasticity assumptions. The skewness (0.41) and kurtosis (-0.18) indicate the distribution of the residuals was approximately normal. The equation includes significant variables that account for 13% of the variance in caregiver depression symptoms.

Table 5

Wife Caregiver, Patient Symptom Global Distress, and Caregiver Support Satisfaction as Predictors of Caregiver Depression Symptoms

Variable	b Parameter Estimate	Standard Error	t value	Pr > t	B Standardized Estimate	Squared Semi-partial Corr Type II
Intercept	7.13653	0.57095	12.50	<.0001	0	.
Wife	0.52639	0.16967	3.10	.0020	0.12120	0.01461
Sx Dist	0.01324	0.00603	2.20	.0284	0.08566	0.00739
Supp.	-0.42958	0.05034	-8.53	<.0001	-0.33353	0.11051

Note: $R^2 = .1291$, $R^2_{adj} = .1244$, Root Mean Squared = 2.01010

Logistic Regression

Correlation with Caregiver Depression Symptom Scores of 4 or Greater

The variable for caregiver depression symptom score was then dichotomized with a score of 0 for a CES-D 10 scores of 3 or less and a code of 1 for CES-D 10 a scores of 4 or greater (n = 578). This was performed to examine predictors of CES-D 10 scores of 4 or greater, which have been found predictive for a diagnosis of depression (Irwin et al., 1999). Univariate statistics showed 62.5% (n = 361) of caregivers had CES-D 10 scores of 3 or less while 37.5% (216) had scores of 4 or greater.

Relationships among the variables were analyzed using point bi-serial and phi correlations (Glass & Hopkins, 1996). Wife caregiver had a low positive significant correlation with and caregiver support satisfaction had a low to moderate negative with significant correlations with CES-D 10 scores or 4 or greater (Table 6).

Table 6.

Wife Caregiver, Caregiver Social Support Satisfaction and Depression Intercorrelations

	CES-D 10 \geq 4	Wife	Supp
CES-D 10 \geq 4	1.000		
Wife	.087	1.000	
	.036		
Supp.	-.239	.073	1.000
	<.000	.075	

Note: CES-D 10 \geq 4 = caregiver CES-D 10 \geq 4, Wife, = caregiver relationship to patient, Supp = patient support satisfaction. Significant correlations are captured in bold.

Logistic Regression Analysis

The two variables correlated with caregiver depression symptoms were entered individually into the regression as predictor variables, based on the prediction model developed from the literature, to explore regression models (Hays, 1994). The resulting regression model included wife caregiver and caregiver support satisfaction as predictor variables, with caregiver CES-D 10 scores of 4 or greater as the dependent variable (n = 578).

The model was statistically significant with chi square (DF = 2) = 39.6155, p <.0001 and all predictor variables statistically significant at alpha .05 (Table 7). The resulting logistic equation was: Caregiver CES-D 10 \geq 4 = 2.7083 + 0.44645 * wife caregiver - .3163 * caregiver support satisfaction. Examining odd ratios, being a wife caregiver was positively predictive of a CES-D 10 score of 4 or greater. A higher score on the caregiver support satisfaction was negatively predictive of a CES-D 10 score of 4 or greater.

Table 7

Wife Caregiver and Patient Support Satisfaction as Predictors of Caregiver Depression Symptoms Scores of 4 or Greater

Variable	DF	b Parameter Estimate	b Standard Error	Wald Chi-Sq	Odds Ratio	95% Wald Confidence Limits		Pr > Chi-Sq
Intercept	1	2.7083	0.6151	19.3856	.	.	.	<.0001
Wife	1	0.4645	0.1801	6.6552	1.591	1.118	2.265	.0099
Supp	1	-0.3163	0.0566	31.2527	0.729	0.652	0.814	<.0001

CHAPTER FIVE

DISCUSSION

Chapter five presents discussion of the research findings. The research question, hypotheses, limitations of the study, implications for health care providers and hospice, and recommendations for future study also are discussed.

Research Question

What is the level of depressive symptoms in hospice cancer caregivers?

In this sample of caregivers of hospice cancer patients, 12.6 % of caregivers reported no symptoms of depression. Of the 87.4 % of caregivers that reported symptoms of depression, 37.5% of those reported a score of 4 or above, predictive for a diagnosis of depression (Irwin et al., 1999). The result is supported by studies that found 32 to 50 percent of caregivers had depressive symptoms at a level suggesting a diagnosis of depression (Covinsky et al., 2003; Butler et al., 2005; Turner, Kaye, Ruffin, & Downey, 2005). The level of caregiver depression symptoms may be a result of the stress of the intense experience of caregiving for end of life patients (Sherwood et al., 2004). Caregivers experiencing depression symptoms may not be able to provide quality care (Thorpe et al., 2006). Caregiver depression symptoms, which may include fatigue, loss of energy and difficulty concentrating, may have difficulty responding to the patient's needs. These needs include personal care, emotional support, pain management and other symptom management. The patient's quality of care and life may be negatively impacted at the crucial stage of the end of life by the caregiver's depression symptoms.

Hypothesis 1

The patient and caregiver factors in the model are correlated with caregiver depression symptomatology.

Patient Variables

The hypothesis is discussed for each of the caregiver and patient fixed and modifiable factors from the Prediction of Caregiver Depression Symptomatology Model (Figure 3). The model was derived from McMillan's Modified Emanuel and Emanuel (1998) Model of a Peaceful Death from the Systematic Assessment to Improve Hospice Outcomes Study.

Cancer Diagnoses and Symptom Distress

None of the patient cancer diagnoses were correlated with caregiver depression symptomatology; therefore, the hypothesis was rejected for patient cancer diagnosis. There was a weak, positive, significant relationship between patient symptom global distress score and caregiver depression symptoms ($p = .021$). However, there was no relationship between patient symptom global distress and caregiver depression symptom score 4 or greater. The hypothesis was therefore partially rejected for patient symptom global distress. Symptom distress was not correlated for depression symptoms of 4 or greater, however it was correlated with depression symptomatology, supporting the findings of earlier studies (Kurtz, Kurtz, Stommel, Given, & Given, 2001; Redeker, Lev, & Ruggiero, 2000; Bambauer et al., 2006; Fleming et al., 2006). Therefore, adequate management of patient symptoms is important for both patient and caregiver well being and quality of life. Caregivers experiencing depression symptoms, as discussed earlier, may not be able to provide adequately patient care.

Functional Status, Depression Symptoms, and Quality of Life

The hypothesis was rejected for patient functional status, and patient symptoms of depression. They were not correlated with caregiver depression symptomatology. The hypothesis was partially accepted for patient quality of life as there was a weak, positive, significant correlation ($p = .045$) between caregiver depression symptoms, but not for scores of 4 or greater. Patient symptom distress has been negatively correlated with patient quality of life (McMillan & Small, 2003). As discussed earlier, caregiver depression symptoms were correlated with patient symptom distress. This finding supports the relationship between caregiver depression symptoms and patient quality of life. Therefore, caregiver depression symptoms may negatively impact the ability to control symptoms, increasing the patient's symptom distress and decreasing the patient's quality of life.

Caregiver Variables

Gender and Relationship to Patient

The hypothesis was rejected as caregiver gender was not correlated with caregiver depression symptomatology. Husband and daughter caregiver were not significantly correlated with caregiver depression. There was a weak, positive, significant correlation between wife caregiver ($p = .022$) and caregiver depression symptoms, including caregiver depression scores greater than 4 ($p = .036$). There was a weak, negative, significant relationship between other caregiver ($p = .005$) and caregiver depression symptoms. Therefore the hypothesis was partially accepted for caregiver relationship to patient. Female caregivers, including spousal caregivers, have been found to have higher depression symptoms (Adams et al., 2002; Cossette, et al., 1995; Covinsky et al., 2003;

Gallicchio, et al., 2002; Mui, 1995; Zanetti et al., 1998). This study found female caregivers, particularly female spousal caregivers, are at greater risk for depression symptoms and depression while caregiving during the intense end of life caregiving experience. Caregivers in the category of other included significant others, sons, sisters, mothers, fathers, and brothers were less likely to have depression symptoms. However, only 12.6% of caregivers reported no symptoms of depression. The overall depression symptom occurrence in all caregivers, regardless of their relationship to the patient or gender, supports the assessment of caregivers for symptoms of depression.

Age and Ethnicity

Caregiver age was not correlated with caregiver depression symptoms, therefore the hypothesis was rejected. There was a weak, negative, significant correlation ($p = .035$) between caregiver ethnicity and caregiver depression symptoms indicating Caucasian caregiver were more likely to have lower depression symptoms scores. However the hypothesis was only partially accepted as caregiver ethnicity was not correlated with caregiver depression score of 4 or greater. The large number of Caucasian caregivers likely influenced the results. An earlier study of 295 African American and 425 Caucasian caregivers found Caucasians had more depressive symptoms than African American caregivers. Social networking and positive aspects of caregiving were suggested as the reason for fewer depression symptoms in African Americans (Williams, 2005). Other studies have reported high depression symptom levels regardless of ethnicity or no difference related to ethnicity (Coon et al., 2004; Adams et al., 2002). Factors other than ethnicity may be more important influences on caregiver depression symptom occurrence and level.

Health Status and Support

Caregiver physical and mental health status were not correlated with caregiver depression symptoms, therefore the hypothesis was rejected. There was a moderate, negative, significant correlation between caregiver support satisfaction and depression symptoms ($p < .000$), including caregiver depression scores of 4 or greater ($p < .000$). Therefore, the hypothesis was accepted. Earlier studies have found caregivers with increased support had fewer depression symptoms, while those with lower social support had increased depression symptoms (Chang et. al., 2001; Grant, 2006; Haley et al., 2003; Williams, 2005). The importance of providing support and assisting caregivers to access support resources is supported by these findings.

Hypothesis 2

The patient and caregiver factors in the model are predictive of caregiver depression symptomatology.

Multiple regression analysis found wife caregiver and patient symptom global distress positively predictive and caregiver social support negatively predictive of caregiver depression symptoms. The other model factors were not predictive (Figure 3). The hypothesis was therefore partially accepted. The results emphasize the increased risk of depression symptoms for female spousal caregivers. The influence of patient symptom distress and caregiver social support on caregiver depression symptoms is further supported by these results.

Hypothesis 3

The patient and caregiver factors in the model are predictive of caregiver depression symptom scores of 4 or greater.

Logistic regression found wife caregiver positively predictive and caregiver support negatively predictive of caregiver depression scores of 4 or greater. The other factors in the model were not predictive (Figure 3). The hypothesis was therefore partially accepted. The results indicate that female caregivers are at higher risk for depression and that social support reduces the risk for caregiver depression.

Regression Summary

The research literature discussed previously supports the positive relationship between wife caregiver and symptom distress with caregiver depression symptoms. The research also supports the negative relationship between caregiver support and caregiver depression symptoms.

Caregiver support satisfaction was a suppressor variable. Suppressor variables are important as they increase effect size and are part of the total variance of the dependent variable (Walker, 2003). Suppressor variables have also been defined as variables that increase the validity of a set of variables in a regression equation (MacKinnon, Krull & Lockwood, 2000).

Limitations of the Study

This secondary analysis used data from a large sample of hospice cancer patients and their caregivers, thus maximizing financial and human research resources with no additional impact of the research on the participants. The focus of hospice care is primarily the care of the patient to minimize suffering at the end of life with the informal caregiver as a partner in the process. The original study was designed to test the intervention of enhanced and structured assessment on caregiver outcomes including depression symptoms. Many instruments were used to measure factors theorized to

impact caregiver depression symptoms, while minimizing caregiver and patient burden of participation. However, this resulted in limitations for this secondary analysis. Other factors known from the literature to be associated with caregiver depression symptoms, such as caregiver burden, history of depression, mastery, and coping were not measured. Measuring only baseline data may not capture factors impacting the prediction of caregiver depression that may intensify as the caregiver experience progresses, such as patient symptom distress and decreases in patient functional status.

Examining instruments used in the study, interpretation problems can arise using the SF-12 summary scales in some analysis, as symptoms in one composite score are likely to produce inflated scores in the other composite. The scale may also produce erroneous results in large studies (Windsor, Rodgers, Butterworth, Anstey, & Jorm, 2006). Other studies have linked depression symptomatology with poor health (Doorenbos et al., 2007; Ferketich et al., 2000; Schulz & Beach, 1999; Vitaliano et al., 2002). Doorenbos et al, using the full version of the CES-D and the SF-36 found lower health status of caregivers of advanced cancer patients associated with caregiver depression symptoms. Considering the CES D10 reported good validity and reliability, the SF-12 may not have adequately measured caregiver mental and physical health in this study. However, it is possible that the shortened version of the CES-D may have contributed to the lack of a relationship of caregiver depression symptoms with caregiver physical and mental health. The correlation between patient MSAS and HQLI-14 was expected as they were correlated in an earlier study using the longer version of the HQLI. However, there was less variance in patient HQLI-14 scores than would be expected for patients in various stages of disease in hospice. The low amount of variance may indicate

patient quality of life was not adequately measured by this shortened instrument. Patient functional status was limited to PPS scores of 40 or greater, which may have affected the relationship of patient functional status and caregiver CES-D 10 score. Social support satisfaction scores tended to be high with limited variance. This may indicate actual social support or that caregivers were not clearly instructed not to refer to support received from hospice when responding to the social support questions on patient admission to hospice. The small number of ethnic minorities in the sample was also a limitation.

Implications for Nursing Practice

Nurses and Nurse Practitioners

Depression symptoms result in suffering for the caregiver and potential loss of the ability to provide quality care to patients at the end of life. Voluntary caregivers will continue to be important sources of care for end of life cancer patients. Many individuals are now part of the sandwich generation of adults taking care of two generations, often their children and parents, at the same time (Wujcik, 2008). These baby boomers, born between 1946 and 1964, have also been referred to as the stretched generation, as caregiving of parents occurs at the same time they are finishing raising their own children (Rogerson & Kim, 2005). Employment and other responsibilities in addition to caregiving may increase the risk for depression symptoms in this stretched generation.

Nurses and nurse practitioners caring for cancer patients at the end of life should be knowledgeable of the symptoms of depression, to adequately provide family centered care to patients and their caregivers. Nurses should screen caregivers for depression or refer for screening as appropriate for their professional role. They should also be aware

of the factors correlated with caregiver depression symptoms, particularly patient symptom distress and patient quality of life. Symptom distress was found predictive of depression symptoms in this study. Efforts to manage patient symptoms and protect quality of life are crucial for an environment that fosters a peaceful death for the patient and reduces the risk of depression symptoms for the patient. Social support was found negatively predictive of caregiver depression symptoms and depression. Nurses and nurse practitioners of end of life cancer patients should foster social support for informal caregivers and assist informal caregivers in identifying social support resources.

In this secondary analysis, more than a third of female and male caregivers had depression symptom scores of 4 or greater on the CES-D 10 on admission to hospice; this is clinically significant. Caregiving by female spouse of cancer patients was found predictive of depression symptomatology and depression. However, caregivers of end of life cancer patients, regardless of gender, are at significant risk for depression symptoms. Given the level of caregiver depression symptomatology found on admission to hospice, assessment of caregivers by their primary care nurses, nurse practitioners, and physicians is important to identify those caregivers at risk for depression symptoms. Nurses and nurse practitioners in primary care should be aware of their patients providing informal care to cancer patients. Identifying patients serving as informal cancer caregivers is important to adequately assess physical and mental health risks during and after the caregiving experience. Early assessment of caregivers at risk for depression may result in early diagnosis and treatment. Voluntary caregivers should be referred for additional screening and treatment as their depression symptoms warrant. Efforts by primary care

providers to foster and increase support for voluntary cancer caregivers are important to protect caregivers' mental and physical health.

Nursing Colleges and Universities

In view of the importance of informal caregivers, nursing college and continuing education courses should include curriculum focusing on the issues confronting informal caregivers. Courses should provide nurses and nurse practitioners with the knowledge and skills necessary to assess and identify voluntary caregivers' physical and mental health risks. Curriculum should also include knowledge of the benefits of involuntary caregiving to the patient, the caregiver and society.

Health Care Policy

Nurses and nurse practitioners should advocate for policies and programs that support the voluntary caregiver. Voluntary caregivers are important partners in providing quality care to patients at the end of life.

Hospice

The sample had a small number of non-Caucasians. More effort is needed to reach out to non-Caucasians to provide and improve access to hospice services. Hospice nurses and nurse practitioners should continue to assess voluntary caregivers for symptoms of depression. Voluntary caregivers should continue to be offered emotional, physical and informational support and assisted in identifying support resources. Hospice should inform voluntary caregivers of the physical and mental health risks associate with caregiving. They should be encouraged to protect their own health by scheduling and keeping appointments with their health care provider for routine and other required care.

Hospice should advocate for policies and programs that support voluntary caregivers as partners in providing care for end of life patients.

Recommendations for Future Study

Depression symptomatology in caregivers of cancer patients near the end of life is multi-factorial. This secondary analysis examined predictors of depression from baseline data from an interventional study. Studies specifically designed to examine predictors of depression symptoms in caregivers of end of life cancer patients should incorporate instruments to measure additional factors associated with caregiver depression symptoms. These factors, such as caregiver history of depression, mastery, burden, coping, attitude, sense of coherence, neuroticism and attitude towards caregiving, should be measured. A future study should focus on these factors associated with caregiver depression symptoms while limiting, as much as possible, the burden to caregiver and patient participants. A longitudinal study would provide data on caregiver depression symptoms during the cancer caregiver experience.

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