

2011

The Mediating Role of Social Support and Fulfillment of Spiritual Needs in End of Life Care

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The Mediating Role of Social Support and Fulfillment of Spiritual Needs in End of Life
Care

by

Kim Gryglewicz

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Social Work
College of Behavioral & Community Sciences
University of South Florida

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Date of Approval:
March 1, 2011

Keywords: Caregiver, Hospice, Stress Process Model, Risk and Protective Factors, Dying

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ACKNOWLEDGEMENTS

First and foremost, this dissertation is dedicated to my loving daughter Mariah and husband Clark. It's been quite a journey with many sacrifices and bumps in the road. I could not have done this without your patience, support and unconditional love. I am profoundly grateful to have had both of you by my side. Your support and encouragement truly inspired me to keep the fire burning and to accomplish my lifelong dream. I could not have done this without you, thank you both.

To the faculty at the University of South Florida, thank you all for sharing your expertise and providing direction and mentorship. To my committee members, Dr. Iraida Carrion—I am truly grateful to have had you on my committee; Dr. Roger Boothroyd—words cannot express how thankful I am to have been under your wing. You have been a wonderful mentor to me over the years; Dr. Nan Park—it has been an honor to work with you. Thank you for your guidance and support; and last but not least, Dr. Susan C. McMillan—*where do I begin?* You have truly been an inspiration to me. I am humbly grateful for your support, guidance and mentorship. I have been blessed to have had the opportunity to work with you. Thank you for inspiring me to never give up on my dreams!

Lastly, to my cohort—thank you all for your friendship and support over the years, especially to Patty, Esther and Erica—you are my three amigos! To my dear friend, Betty Lou—we traveled many roads together. Thank you for your friendship and

for sharing this experience with me. To all of the hospice caregivers we interviewed, I am sincerely grateful to you all. Thank you for allowing us into your homes.

This study was completed while the author was a student in the Ph.D. program in the School of Social Work at the University of South Florida.

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ABSTRACT

End of life (EOL) caregiving can be a daunting and challenging endeavor as caregivers adjust to the ever-changing care demands associated with dying. Increased personal care, assisting with symptom and medication management, and attending to the emotional and spiritual needs of the dying person require caregivers to learn new tasks and to assume new roles such as social worker, nurse, and chaplain. As families continue to play an essential role in meeting the health care needs of their dying loved ones, it is imperative for social workers to understand the complexities of the end of life caregiving experience in order to better serve this population. One way to better understand this experience is by examining it within the context of the *stress process model* of caregiving. This model provides a comprehensive way to examine the relationship among multiple risk and protective factors within the “caregiver-in-environment” context. Using a secondary dataset, the best fit predictive model of caregiver depression included a mix of sociodemographic characteristics, primary objective and subjective stressors, and mediating variables. Two protective factors, social support and the fulfillment of spiritual needs lessened the effects of caregiver depression among the most vulnerable caregivers. Findings from this study help to bridge the gap between theory and social work practice. The stress process model of caregiving is a well-tested theoretical model, which can be utilized to guide social workers in developing

comprehensive assessment measures and interventions that target specific aspects and sources of stress within the EOL caregiving experience.

CHAPTER 1: INTRODUCTION

Adults aged 65 years and older are one of the fastest growing populations in the U.S. It is estimated that this population will double in size from 35 million in 2000 to approximately 72.1 million by 2030. The oldest segment of our population, those 85 years and older, is also expected to double in size from 4.2 million in 2000 to 8.7 million by 2030 (Administration on Aging [AOA], 2009). As our society continues to “gray” so does the prevalence of chronic conditions and illnesses and the need for both formal and informal types of care.

Currently, 4 out of 5 older adults suffer from at least one debilitating condition, and the likelihood of developing other serious chronic conditions, such as dementia and heart disease significantly increases with age (AARP, 2009). The risk of being diagnosed with cancer, another common ailment in old age, is also expected to increase by 67 percent by 2030 (Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009). These chronic conditions will require various levels of care. Informal caregiving (i.e., unpaid care provided by family or friends) is and will continue to play an essential role in meeting the health care needs of older adults.

Informal Caregiving

In the United States alone, there are approximately 43.5 million caregivers who provide unpaid care to family members or friends 50 years and older (National Alliance for Caregiving [NAC] & AARP, 2009). This number is also expected to rise with the changing demographics of older adults. An aging society, coupled with the astronomical costs associated with long-term care, fragmented and uncoordinated systems of care, workforce shortages, and care recipients' (CRs) desire to be cared for at home, increases the need and demand for informal caregiving, making it an increasingly invaluable service (Family Caregiver Alliance, 2004; U.S. Department of Health and Human Services [USDHHS], 2003).

The economic, social, and familial value of caregiving is not without consequence. Caregiving can have a negative impact on the physical, psychological, social, and spiritual well-being of caregivers. Research has documented that caregiving poses an increased risk for depression and anxiety (Cannuscio et al., 2002; Mahoney, Regan, Katona, & Livingston, 2005; Pinquart & Sorensen, 2006; Yee & Schulz, 2000). It can also negatively impact physical health by impairing immune functioning and increasing the vulnerability to infectious illnesses (Gourin, Hantsoo, & Kiecolt-Glaser, 2008), as well as by increasing the risk of developing chronic conditions such as cardiovascular disease (Aschbacher et al., 2007; Lee, Colditz, Berkman, & Kawachi, 2003) and stroke (Haley, Roth, Howard, & Safford, 2010).

The caregiving role can also impact other domains of a caregiver's life. Juggling caregiving responsibilities with work obligations has been found to be quite burdensome, placing some families, in particular younger and middle-aged caregivers in financial

turmoil (NAC & AAPR, 2009; Schulz et al., 2003). Having to make work accommodations such as reducing work hours, taking time off, and/or resigning from a job can lead to substantial losses in earnings and benefits as one study found caregivers to lose an average of \$659,000 in total wealth (MetLife Mature Market Institute, NAC, & National Center on Women and Aging, 1999). Moreover, some caregivers may experience additional strains from being “sandwiched” between caring for frail loved ones to caring for and supporting children and/or grandchildren (Hammer & Neal, 2008).

Impact of End of Life Caregiving

For families and friends who undertake end of life (EOL) caregiving responsibilities, it can be an even greater challenge. Caregivers not only have to come to terms with their loved ones’ terminal diagnosis and impending death, but they must also adjust to the ever-changing care demands associated with dying (Glajchen, 2004; Haley, 2003; McMillan, 2005). Increased personal care, assisting with symptom and medication management, and attending to the emotional and spiritual needs of the dying person may require caregivers to learn new tasks and to assume new roles such as social worker, nurse, and chaplain.

EOL caregiving can seem like a full-time job as caregivers spend countless hours trying to meet the needs of their loved ones. For example, in one study, Wolff, Dy, Frick, and Kasper (2007) found that nearly 85% of caregivers reported spending an average of 43 hours a week providing care. Haley and colleagues (2001) found that EOL caregivers devoted more than 120 hours of weekly care; and yet in another study, more than 50% of caregivers felt as if they were “on duty” 24 hours a day (Schulz et al., 2003). These researchers found that the demands associated with EOL care can increase the risk for

caregiver depression. In addition, these caregivers are at a greater risk of experiencing physical problems such as sleep disruption and fatigue (Glajchen, 2004), which in turn may lead to other health ailments, and even increase the risk of mortality (Schulz & Beach, 1999).

EOL caregivers also must deal with other challenges. They may need to make major adjustments to their daily schedule, whether this is making accommodations at work, tailoring household chores around caregiving activities, or planning time to accommodate for visits from the hospice team and/or social visits from family or friends (Haley, 2003; McMillan, 2005). All too often, caregivers find themselves withdrawing from social activities and roles, and may even neglect their own health due to the time and commitment devoted to providing care (Chentsova-Dutton et al., 2000).

Research has clearly documented that EOL caregiving can have a detrimental impact on the overall well-being of caregivers. EOL caregiving has been found to impact daily schedule (Jo, Brazil, Lohfeld, & Willison, 2007), subjecting caregivers to greater strain (Redinbaugh, Baum, Tarbell, & Arnold, 2003) and psychological distress (Dumont et al., 2006). In one study, over 70% of caregivers experienced at least one type of strain, with psychological, physical, and social strain being most problematic (Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010). Caregiver strain and distress has also been associated with adjustments to the caregiving role and/or witnessing their loved one's suffering (Glajchen, 2004).

Within quality of life (QOL) domains, EOL caregiving has been associated with poorer functioning across emotional and spiritual domains (Kim, Baker, & Spillers, 2007). In particular, significant declines in social, emotional, and overall QOL have been

reported among caregivers of recently admitted hospice patients (Wilder, Oliver, Demiris, & Washington, 2008). These researchers purported that declines in emotional and social QOL may reflect the start of the grieving process and the need to withdraw and detach from social networks. EOL caregiving also appears to be associated with greater physical strain (Gustavson & Dal Santo, 2008) and overall poor physical QOL (Weitzner, McMillan, & Jacobsen, 1999).

The costs associated with EOL caregiving can also contribute to financial strain and burden. In a study of former EOL caregivers, Tilden, Tolle, Drach, and Perrin (2004) found that a majority of caregivers encountered financial hardships as a result of caregiving. Families often spent their own money to pay for expenses such as medication, transportation, and medical equipment. As expected, these researchers found that greater financial strain contributed to greater caregiver strain. In a qualitative study conducted by Jo et al. (2007) similar financial burdens emerged. One family member described the feeling of drowning in debt, while another felt overwhelmed with the exorbitant costs associated with medical expenses. Such debt can cause some families to take out financial loans, sell assets, and/or seek additional employment (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). For the EOL caregiver, these additional strains can further exacerbate the caregiving experience, increasing the risk for depression.

For those who care for dying individuals, their journey may be marked with both positive and negative experiences. End of life caregivers are in a position to honor their loved ones' wishes to die at home. They are also able to try to make the dying experience a peaceful one—one that can be characterized as a good death (i.e., a death free from distress and suffering and in accordance with the wishes of the care recipient

(CR) and/or family) (Emanuel & Emanuel, 1998; Munn & Zimmerman, 2006). For the spouse, adult child, family member or friend who provides care, this time can be devoted to resolving issues, reminiscing, and saying goodbye.

However, as research has documented, EOL caregiving can also capture experiences that are far from positive. Research clearly shows that the ongoing demands of EOL care can place some caregivers at a greater risk for depression (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Doorenbos et al., 2007; Given et al., 2004; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Haley et al., 2001; Herbert & Schulz, 2006; Schulz et al., 2003). Since social workers are perceived as key providers of social support (Raleigh, Robinson, Marold, & Jamison, 2006), they are in an ideal position to help minimize self-neglect, fatigue, burden, and depression. Through the use of ongoing standardized assessments, social workers can work with the family system and hospice team to improve communication and identification of needs, which in turn may help to enhance the QOL for patients and their caregivers (Wilder et al., 2008).

The Role of Social Work in Hospice Care

As our society ages, informal caregivers will continue to play an integral role in our healthcare system. Quality health care services will need to be in place to meet the ever-changing needs of CRs and caregivers. Failure to address such needs may result in significant strains to both the family and healthcare system. Social workers, in particular, have the opportunity to improve the quality of care and services provided to this growing population of informal caregivers.

Social work's person-in-environment perspective and focus on *starting where the client is* exemplifies the unique approach social workers bring to different service

delivery systems, including hospice care. With an emphasis on examining the biopsychosocial, spiritual, cultural and economic aspects of the client and family system, a common perspective utilized in social work practice, social workers are in ideal roles to develop, implement, and evaluate care plans and interventions. As members of interdisciplinary teams, social workers can utilize their knowledge and skills to provide comprehensive care that strives to meet the needs and perspectives of patients and families while at the same time upholding social work ethics and principles such as respect for persons and relationships, valuing the inherent dignity and worth of persons, and promoting self-determination (NASW, 2004). The underlying principles and values that social work shares with EOL care further accentuates the value of the social work role in hospice settings (Gwyther et al., 2005).

Yet, despite the value of social work's role in hospice and palliative care, some social work scholars suggest that the "profession is playing 'catch up' and chasing opportunities to collaborate, lead and enrich both the care and the literature emerging in this field of practice" (Altilio, Gardia, & Otis-Green, 2007, p. 83). Scholars advocate for the advancement of well-conceptualized studies that aim to advance social work practice and research (Gwyther et al., 2005). In order to clarify the social work role, advance our position within interdisciplinary settings, and address gaps in the social work literature, Gwyther and colleagues direct social workers to examine the physical, emotional, social, and/or spiritual dimensions of living with and caring for those who are in the final stage of life. To address this gap in the literature, this study utilized an empirically supported model to examine the biopsychosocial-spiritual dimensions within the EOL caregiving experience.

Purpose of the Study

In order to promote preventative behaviors and practices that can help safeguard caregivers from psychological distress, it is critical for social workers to understand the complexities of the EOL caregiving experience. Social workers need to be able to identify and understand the various stressors, or “risks” that may impair the caregiver’s ability to provide adequate care to oneself as well as to the CR. They must also be able to identify the various resources, or “protective factors” that promote resiliency.

The National Agenda for Social Work Research in Palliative and End of Life Care calls for social workers to engage in research aimed to understand the diverse needs of dying individuals and families, in addition to improving the efficacy and delivery of services provided to this population (see Kramer, Christ, Bern-Klug, & Francoeur, 2005 for review). To address some of the core priorities set forth in this agenda, this study aimed to examine the EOL experiences and needs of CRs and caregivers. Specifically, this study examined the various psychosocial factors that predict caregiver depression among hospice caregivers of terminally ill cancer patients.

One of the core objectives outlined in the National Agenda is to “examine risk and protective factors: predictive, mediating, and moderating factors that impact the response and outcomes” among EOL care populations (Kramer et al., 2005, p. 427). One way to better understand the EOL caregiving experience is by examining it within the context of the *stress process model* of caregiving (Pearlin, Mullan, Semple, & Staff, 1990). This model provides a comprehensive way to examine the interconnectedness between risk and protective factors and how these factors impact the overall caregiving experience. By utilizing components from the stress process model of caregiving, this

study aimed to (a) identify primary stressors that predict caregiver depression (b) identify coping resources that mediate the relationship between caregiver depression and primary objective and subjective stressors, and (c) identify sociodemographic variables that place caregivers at a greater risk of experiencing caregiver depression.

As Bern-Klug, Kramer, and Linder (2005) assert, social workers should strive to improve the quality of care and services provided to EOL care populations by implementing services, practices, and interventions that best meet the needs of dying individuals, families, and communities. One way social workers can enhance their knowledge and skills is by developing and testing comprehensive, theoretical frameworks or models that can guide social work practice and research. Such models can be used as a foundation to guide social workers to develop “reliable, valid, and practical” assessment measures and interventions (Kramer et al., 2005, p. 427). Therefore, the goal of the study was to examine the stress process model of caregiving in predicting risk and protective factors among older hospice caregivers.

Research Questions

The following research questions guided the study:

- 1). What are the best predictors in identifying caregiver depression among hospice caregivers? More specifically,
 - a). What is the relationship between caregiver depression and sociodemographic characteristics (i.e., age, gender, work status) of CRs and caregivers?
 - b). What is the relationship between caregiver depression and primary objective stressors (i.e., CR's functional and cognitive statuses, QOL, symptom distress)?
 - c). What is the relationship between caregiver depression and primary subjective stressors (i.e., physical and emotional health)?
 - d). Do certain resources (i.e., social support and fulfillment of spiritual needs) mediate the relationship between caregiver depression and sociodemographic characteristics, primary objective stressors and primary subjective stressors?

CHAPTER 2: LITERATURE REVIEW

This literature review provides an overview of the theoretical framework and previous research that undergirds this study. The review begins by presenting the classic work of Hans Selye (1976), the concept of stress, and the physiological reactions individuals experience when exposed to stressors. Lazarus and Folkman's (1984) transactional stress and coping theory is then presented to give the reader a better understanding of the unique internal processes individuals ascribe to during situations and events that invoke stress. Finally, a review of the EOL and cancer caregiving literature, in conjunction with the stress process model of caregiving (Pearlin et al., 1990) is described. Key concepts are also operationalized.

Stress Theory

The human stress phenomenon has been around for decades, with its most notable work deriving from Hans Selye (1976) and his concept of "stress." Selye defined stress as the "nonspecific response of the body to any demand" (p.14). He believed that stressors, albeit emotions or situations, evoke universal, physiological reactions which can be objectively measured. Based on Selye's stress theory, the body reacts to stress in sequential phases beginning with an alarm stage, a period marked by somatic shock; the resistance stage, a period where the body attempts to return to a level of homeostasis; and

the exhaustion stage, a period where the body depletes “adaptive energy” and becomes exhausted. Exposure to ongoing stress can eventually lead to physical and/or psychological conditions.

However, not everyone reacts to an event or experience in the same way. Such variation can be explained by personal and situational factors that constantly influence the way individuals think about and ascribe meaning to events or situations. Based on transactional stress and coping theory, cognitive appraisal is the key mechanism that enables the self to discriminate if, and to what extent, there is harm, and how to mitigate such harm (Lazarus & Folkman, 1984). These processes are constantly in operation and are dictated by “transactions” or changes within the person and environment relationship. The concept *stress* is therefore better defined as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well being” (Lazarus & Folkman, p. 19).

There are two types of appraisal processes that are in perpetual motion with each other: primary and secondary. These processes work interdependently to evaluate and determine how the self will cope with threats. Primary appraisal processes determine whether or not an event or situation is deemed as (a) irrelevant, or valueless; (b) benign-positive, or harmless; or, (c) stressful, to what extent the event poses harm, loss, threat, or challenge. Secondary appraisal processes evaluate how the self will cope with an event or situation. During this process, the self constantly appraises and reappraises situations to determine the potentiality for harm, and whether or not one’s capacities, resources, and/or coping strategies will mitigate such harm (Lazarus & Folkman, 1984).

When an individual appraises a situation as being stressful or threatening, coping processes are then employed to manage specific external and/or internal demands that exceed the resources of the person (Lazarus, 1993). Coping is defined as “ongoing...cognitive and behavioral efforts to manage psychological stress” (Lazarus, p. 237). According to Lazarus, there are two functions of coping: emotion-focused and problem-focused. Emotion-focused coping attempts to regulate emotional reactions relating to the appraised situation. Problem-focused coping attempts to manage or alter stressful situations by utilizing action-oriented strategies. In addition, coping resources such as a strong social support system, positive beliefs, internal locus of control, and spirituality help to mitigate the effects of stress.

Stress Process Model of Caregiving

EOL caregiving has been identified as a major life stressor due to the various demands and challenges imposed on the caregiver (Haley et al., 2003; Weitzner, Haley, & Chen, 2000). Over time, such demands may be appraised as overwhelming and burdensome, resulting in stress. Caregivers who are unable to utilize resources that help protect them from ongoing stressors may experience what is known as caregiver stress. According to Pearlin et al. (1990), caregiver stress should not be thought of as a static or “unitary phenomenon,” but instead should be viewed as a “mix of circumstances, experiences, responses, and resources that can vary considerably among caregivers and that, consequently, vary in their impact on caregivers’ health and behavior” (p. 591). For some caregivers, certain stressors may threaten the perceived ability to provide care, which in turn may lead to feelings of despair and inadequacy. For others, certain

“resources” help to buffer the effects of stressors, thus protecting the self from psychological or physical distress.

Caregiving has often been studied using stress and coping frameworks or models (e.g., Haley, Levine, Brown, & Bartolucci, 1987; Pearlin et al., 1990; Weitzner et al., 2000). These models examine the various conditions or processes in which stress arises, develops, and changes over time. Within the stress process model of caregiving proposed by Pearlin and colleagues, there are four domains or components which capture stress process outcomes: background and contextual factors, primary stressors, secondary stressors, and mediating variables or resources (Figure 1). A description of the stress domains, with selected research on EOL and cancer caregiving is outlined.

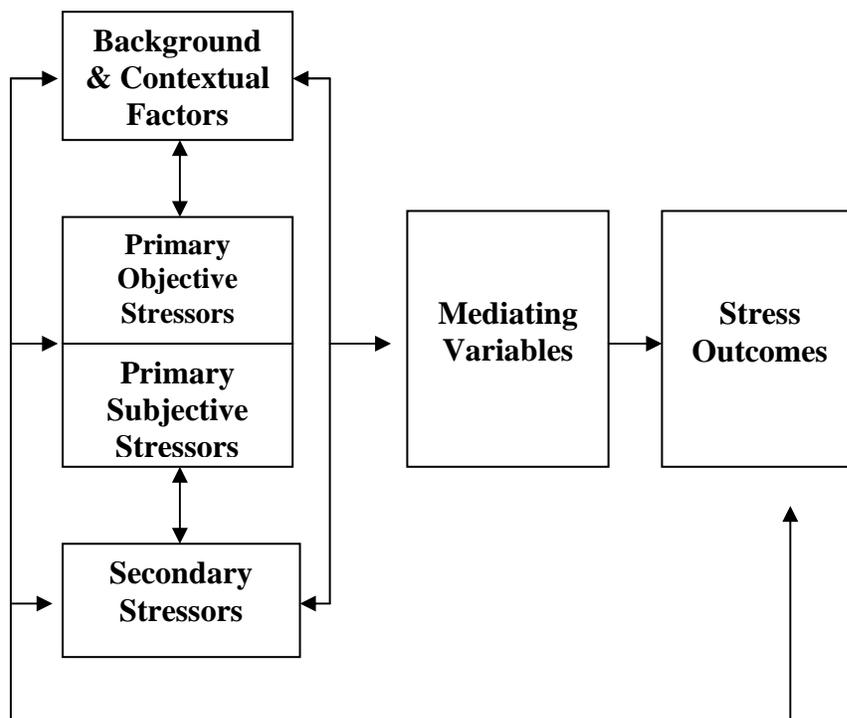


Figure 2. The Conceptual Stress Process Model of Caregiving. Adapted from Pearlin, Mullan, Semple, & Staff’s (1990) conceptual model of caregiver stress.

Background and contextual factors. Background and contextual factors are defined as the sociodemographic variables or characteristics of the caregiver and CR (Pearlin et al., 1990). These factors may influence the caregiver's exposure to certain stressors and/or ability to acquire or utilize resources. Examples include age, gender, marital status, income, relationship to the CR, and caregiving history. The inclusion of background and sociodemographic characteristics within the stress process model enables researchers to identify caregivers who may be at a greater risk of experiencing stress.

Gender. It is well established that the bulk of family caregiving falls on women (Navaie-Waliser, Spriggs, & Feldman, 2002; Yee & Schulz, 2000). Whether this is due to cultural traditions or gender role beliefs and expectations, women assume the caregiving role despite work and other familial obligations. When compared to male caregivers, research reveals some distinct gender differences. In general, men are more likely to view the caregiving experience as rewarding and are less likely to report negative impacts to health and overall well-being (Kim et al., 2007; Yee & Schulz). Such differences may be due to better coping strategies or other internal resources that protect the self from harm (Kim et al.; Nijboer, Tempelaar, Triemstra, Sanderman, & van den Bos, 2001a).

For example, in a study conducted by Nijboer et al. (2001a) self-esteem appeared to play an important role in predicting health outcomes. In this study, male caregivers were much more likely to possess higher levels of self-esteem than female caregivers, and as a result were more likely to report better physical and mental health functioning at 3 and 6-month follow-ups. Similar findings emerged in another study that examined gender differences among cancer caregivers (Kim, Loscalzo, Wellisch, & Spillers,

2006b). Results from this study suggested that reliance on internal resources such as self-esteem helps to safeguard caregivers, particularly men, from the negative impacts of stress.

Conversely, research on female caregivers suggests that women respond to stressors with greater emotionality—that is greater burden and distress than men (Pinquart & Sorensen, 2006). Female caregivers have been found to report higher levels of depression (Haley et al., 2003); engage in unhealthy behaviors (i.e., self-medication and alcohol use) (Matthews, Baker, & Spillers, 2003); report lower levels of life satisfaction (Haley et al., 2001); have problems adjusting to the caregiving role (Northouse, Mood, Templin, Mellon, & George, 2000), and report more unmet needs and disruptions in daily schedule (Ussher & Sandoval, 2008).

In a study that examined the effects of gender on adjustment to cancer, Northouse and colleagues (2000) found that females reported significantly greater levels of emotional distress and role adjustment than males. The combination of being a female and a caregiver appeared to have an “additive effect” on coping ability. Female caregivers experienced a greater amount of concurrent stress, emotional distress, and problems adjusting to their spouses’ illness after diagnosis, 60 days post surgery, and at one year follow-up. These authors purported that gender differences found in this study may be due to multiple role demands, greater sensitivity to their loved ones’ problems, and limited or taxed resources on female caregivers. Other research suggests that female caregivers may be more vulnerable to stress because they are more likely to provide greater care tasks; may be less likely to seek help from others; and less likely to utilize effective coping strategies and internal resources (Yee & Schulz, 2000).

Although these studies provide evidence to support the notion that female caregivers are more likely to experience greater levels of distress than males, some research suggests that male caregivers are just as vulnerable to the negative impacts of care-related stressors, especially when positioned in caregiving roles that threaten one's identity and perceived capability to provide care (Kim et al., 2006b). Gender role perspectives and theories provide some explanation as to why gender differences exist. For example, Hagedoorn, Sanderman, Buunk, and Wobbles (2002) assert that gender differences in caregiver outcomes stem from "differences in identity-relevant stressors between women and men" (p. 490). These researchers purport that differences between male and female caregivers emerge when caregivers question their ability to provide adequate care. In a sense, failure to provide such care can result in negative feelings towards one's sense of self or identity.

In their study, Hagedoorn et al. (2002) found support for the "identity-relevant stress" hypothesis. They found that caregivers who felt less competent in their roles were more likely to experience psychological distress than caregivers who felt they were doing a good job, and the caregivers who felt incompetent were females. Results from this study suggest that women tend to internalize the caregiving role as part of their identity, whereas men may not.

The work of Ussher and Sandoval (2008) uncovered similar findings to suggest that differences among male and female caregivers may be due to the way they are positioned within the caregiving role. Such positioning may reflect the way the self identifies one's role and/or by how others perceive it. Findings from Ussher and Sandoval's study found that women tend to internalize their role as "all encompassing

expert carers” who unselfishly devote time and energy towards providing care (p. 951). Women provided around the clock care, often neglecting their own health and needs, which in turn resulted in negative feelings and emotions. Male caregivers, on the other hand, were positioned in roles that reflected tasks that were concrete in nature. Tasks such as bathing or administering medications could be mastered or accomplished which resulted in feelings of competence. These findings may explain why male caregivers view the caregiving role as rewarding.

However, when faced with having to deal with emotional work, male caregivers appear to have some difficulty not only coping with their CR’s feelings but their own feelings as well. Ussher and Sandoval (2008) provide some explanation as to why male caregivers may be more reluctant to openly share and express their emotions and feelings. They assert that such behaviors may be a way to uphold gender role expectations. Kim et al. (2006b) attribute such findings to the “gender role socialization perspective” (Gilligan, 1982, as cited by Kim et al.) which purports that males are traditionally socialized to be problem solvers (p. 1086). Physical care tasks may be viewed as work that can be accomplished and mastered. When male caregivers are placed in a position where they may feel the need to resolve CR’s emotions or feelings, a task that may not be easily amendable or fixable, feelings of stress, incompetence, or guilt may emerge. These findings provide some evidence to suggest that male caregivers are not immune to the negative effects of caregiver stress.

Relational characteristics between caregiver and care recipient. The caregiver’s relationship to the CR can also impact the caregiving experience. Some researchers have found older caregivers, usually spouses, to be at a greater risk for psychological and/or

physical morbidity (Braun et al., 2007; Haley et al., 2001); while others have found younger caregivers, usually adult children, to be more at risk (Given et al., 2004; Kim et al., 2007). According to Lowenstein and Gilbar (2000) such differences may be due to the way caregivers perceive their role and place within the life cycle. Spouses, for example, may be more vulnerable to distress due to role expectations within marital relationships. They are often obligated not only to maintain the caregiving role for longer periods of time but are also expected to provide various levels of care, including personal care. Spousal caregivers may also endure greater strains due to physical (i.e., declining health) and social (i.e., lack of social support) limitations. Ironically, such limitations often result from being older in age. On the other hand, adult child caregivers, especially daughters, may be more vulnerable to distress due to the various roles and responsibilities they assume. These caregivers may be more likely to experience restrictions to their daily schedule as they try to find a balance between competing role demands.

In general, research on spousal caregivers of cancer patients has revealed a number of negative outcomes. For instance, in a study that examined the perceptions of caregiver burden, Lowenstein and Gilbar (2000) found that spouses experienced significantly higher levels of personal strain and overall burden than adult child caregivers. Spousal caregivers were more likely to perceive the caregiving experience as being stressful and overwhelming. Jo and colleagues (2007) found that spouses commonly reported physical, emotional, and financial strains, along with restrictions on time. Demands associated with care often left caregivers feelings fatigued and depressed. Increasing care demands have also been shown to substantially impact daily schedule,

resulting in negative caregiving experiences in other studies (Doorenbos et al., 2007; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

In their review of the literature, McLean and Jones (2007) found that spouses commonly experienced clinical levels of distress, often reporting similar levels as CRs. In a study that examined the physical and psychological health among hospice caregivers, Haley et al. (2001) found that spouses were susceptible to poor physical health, low levels of life satisfaction, and depression. More than 50% of caregivers in this study scored beyond the clinical threshold for depression. Other studies have found similar clinical ranges (Braun et al., 2007; Given et al., 2004). Depression and risk of complicated grief, including suicidal ideation are other serious problems impacting bereaved spouses, especially among widows who have limited support networks (Stroebe, Stroebe, & Abakoumkin, 2005).

Research on adult child caregivers reveal that they, too, are likely to experience negative impacts to overall functioning and health. In a study that examined the effects of gender, relationship to the CR, and the appraisal process, Kim and colleagues (2007) found that adult children were significantly more likely to perceive the caregiving role as stressful. As a result, these caregivers were more likely to report greater levels of psychological distress and poorer mental functioning and spiritual adjustment than spousal caregivers. Adult daughters in particular fared the worst, reporting the highest levels of caregiver stress. Greater filial obligation and negative appraisal of the caregiving role (i.e., caregiver overload) led to higher levels of anxiety among adult daughters in another study (Raveis, Karus, & Pretter, 1999).

In a study that examined the relationship of CR and caregiver variables in predicting caregiver burden and depression, Given and colleagues (2004) found that adult children reported the highest levels of depression, feelings of abandonment, and impacts on daily schedule. In particular, when compared to spouses, adult children were more likely to report depressive symptoms especially as CRs neared death. They were also more likely to experience substantial impacts on daily schedule particularly when the number of cancer-related symptoms increased. Adult children who were employed experienced the greatest impact. It appeared that having to juggle caregiving tasks with non-caregiving tasks (i.e., work) led to substantial impairments to overall emotional health. As adult children engage in ongoing care demands, time for oneself becomes limited. In fact, research has documented that restrictions in normal, daily activities leads to isolation and caregiver distress (Cameron, Franche, Cheung, & Stewart, 2002; Goldstein et al., 2004).

Overall, research suggests that both adult child and spousal caregivers encounter significant problems adjusting to the caregiving role. Both groups, for various reasons, have been found to experience psychological and social distress (Chentsova-Dutton et al., 2000) as well as report similar levels of depression, grief, and other forms of distress during prebereavement and postbereavement periods (Chentsova-Dutton et al., 2002). In order to gain a more comprehensive understanding of the caregiving situation across gender and relationship to the CR, it is necessary to examine the relationship with other risk factors.

Primary objective stressors. Stressors are defined as “the conditions, experiences, and activities that are problematic for people; that is, that threaten them,

thwart their efforts, [and] fatigue them” (Pearlin et al., 1990, p. 586). There are two types of stressors, primary (objective and subjective) and secondary. Objective primary stressors stem directly from the CR’s disease, and reflect the care needs and related caregiving tasks to meet such needs. These needs can fluctuate based on illness and level of impairment and may intensify over time. Examples include the CR’s diagnosis and prognosis, as well as cancer-related symptoms such as level of pain, cognitive impairment, mood, and behavioral problems.

Cancer diagnosis and prognosis. The diagnosis and prognosis of end-stage cancer can impact the physical and emotional state of caregivers. In a recent study that examined cancer caregiving experiences, Doorenbos et al. (2007) found distinct differences in burden and depression among caregivers who provided care to CRs nearing death versus CRs with longer survival statuses. Although results revealed that all caregivers experienced increases in depressive symptoms following the diagnosis of the CR, caregivers who provided care to end-stage cancer patients scored near the clinical threshold for depression. These caregivers, who were mostly spouses, also experienced greater impacts to daily schedule. The authors suggested that the diagnosis of end-stage cancer can place some caregivers at an increased risk for depression due to the inability to grieve and cope with their loved ones’ poor prognoses. Another study found differences in psychological well-being among caregivers who cared for CRs during palliative and terminal stages (Grunfeld et al, 2004). Although most caregivers experienced psychological distress during both stages, it was during the terminal stage when caregivers felt more depressed and had higher levels of burden.

Other studies have had similar findings. For example, Kurtz and colleagues (1994) found that as CRs neared death, caregivers became more involved in their loved one's care; they experienced greater impacts to their health and daily schedule, and, reported higher levels of depression. In addition, they found that as cancer-related symptoms and dependency worsened, support from family and friends diminished which left "couples to face a social death long before the physical death occurred" (p. 2078). Moreover, Dumont and colleagues (2006) found a direct relationship between the functional status of CRs and caregiver distress. In this study, caregivers who provided care to debilitated, bed-bound cancer patients experienced the highest levels of psychological distress and burden. These research findings provide support to suggest that EOL caregiving can lead to substantial impairments in overall well-being.

Cancer-related symptoms. Individuals who are diagnosed with cancer often experience a variety of distressing symptoms that can negatively impact overall well-being. Symptoms such as constipation, pain, and psychological distress have been found to negatively impact QOL (Kutner, Bryant, Beaty, & Fairclough, 2007; McMillan & Small, 2002). Fatigue, worrying, feeling nervous, and dyspnea have been associated with depression (McMillan & Rivera, 2009). Pain has been found to have a profound effect on other symptoms, creating what is known as a "synergistic effect." In other words, the presence of multiple symptoms (i.e., clustering of symptoms) can have a "catalytic effect on one another," which in turn can lead to greater levels of distress (Kurtz, Kurtz, Given, & Given, 2007, p. 105). For example, the presence of distressing physical symptoms can exacerbate pain levels (Kutner et al., 2007) and negatively impact QOL and psychological well-being (Fox & Lyon, 2006; McMillan & Rivera, 2009).

As caregivers provide care to terminally ill patients, they may be affected by their loved ones' symptoms, or suffering. Sherman (1998) describes this effect as reciprocal suffering, where the suffering of the CR is shared with the caregiver. Various studies have demonstrated this phenomenon. For instance, patient immobility, increased symptomatology, and symptom distress have been associated with caregiver burden and depression (Andrews, 2001; Given et al., 2004; Kurtz, Kurtz, Given, & Given, 1995). Declining physical health status of the patient has been shown to negatively impact caregiver QOL (Weitzner et al., 1999) and has been associated with caregiver depression and anxiety (Grunfeld, et al., 2004). Moreover, declines in psychological and spiritual well-being have been found to increase levels of caregiver strain (Redinbaugh et al., 2003).

Care needs and tasks. Caregiving requires a lot of time and energy from the caregiver, especially when care tasks are complex as is the case in EOL care. Research has revealed that EOL caregiving can feel like a full-time job as caregivers spend countless hours providing care (Haley et al., 2001; Kim & Schulz, 2008; Wolff et al., 2007). End of life care has been found to increase feelings of burden and strain (Kim & Schulz; Redinbaugh et al., 2003), create disruptions in daily schedule (Nijboer et al., 1999), especially restricting activities outside of the caregiving role (Cameron et al., 2002). Intense levels of care have been associated with loss of intimate exchange, role captivity (i.e., feeling trapped within the caregiving role), and fatigue (Gaugler et al., 2005). In addition, complex personal and nursing care tasks can leave some caregivers feeling inept in their ability to provide care (Andrews, 2001). As a result, some caregivers may be more vulnerable to feelings of inadequacy and low self-esteem, which

in turn may lead to impairments in caregiver functioning. Based on some research, caregiver outcomes have been better explained by the way caregivers subjectively appraise the caregiving role (Gaugler et al., 2009; Haley et al., 2003; Nijboer et al., 1999).

Primary subjective stressors. Subjective primary stressors reflect the caregiver's emotions or perceptions relating to care tasks, the disease process, and caregiving experiences (Pearlin et al., 1990). Examples of subjective stressors include feelings of burden, role strain, and low self-efficacy. Based on stress and coping theory (Lazarus & Folkman, 1984), the appraisal process plays a significant role in caregiver outcomes. Therefore, depending on the context of the caregiving situation and the accessibility of internal and external resources, some caregivers may be more likely to appraise the caregiving role in a negative way, while others may not.

For instance, in a study that examined perceptions of the caregiving experience, Kim and colleagues (2007) found that caregivers who appraised the caregiving role as esteem boosting were more likely to report better overall QOL, especially within psychological, mental, and spiritual domains than those who appraised the role as being stressful. Matthews et al. (2004) found that negative perceptions of the caregiving experience, in particular feeling overwhelmed and entrapped in the caregiving role, resulted in poorer QOL and spiritual distress. Role captivity, role overload, and negative perceptions proved to be strong predictors of caregiver depression, negative health, and dissatisfaction in life in other studies as well (Gaugler et al., 2009; Haley et al., 2003). In a sense, caregivers who appraise the caregiving role as being stressful or overwhelming may be less likely to view the caregiving situation in a meaningful way. These caregivers

may be more vulnerable to declines in overall physical health (Pinquart & Sorensen, 2007), which in turn may increase the risk of mortality.

Health. Another variable that may serve as either a risk or protective factor for caregivers is health. In general, caregivers who perceive their health as being good tend to experience lower levels of caregiver strain than those with poorer health (Bainbridge, Krueger, Lohfeld, & Brazil, 2009). For caregivers who report being in poor health, the caregiving role can be a daunting one as they struggle to care for CRs needs as well as their own. The resulting impact often leads to psychological distress and poorer QOL (Dumont et al., 2006; Haley et al., 2003; Lim & Zebrack, 2004; Tang, 2009). Poor health is also associated with older age, which offers some explanation as to why older adults, who are usually spouses, are more vulnerable to distress (Doorenbos et al., 2007; Navaie-Waliser et al., 2002).

Conversely, caregivers who are in good health may be more likely to handle care tasks simply because they have more energy and stamina. In addition, these caregivers may be more likely to engage in healthy behaviors and practices (e.g., exercise, meditation, good nutrition). In a study conducted by Matthews et al. (2004), greater practice of healthy behaviors significantly predicted better overall QOL. Caregivers who specifically engaged in healthy behaviors were less likely to feel socially isolated and trapped in the caregiving role. These caregivers were also more likely to experience greater physical and psychological well-being. Engaging in healthy behaviors not only serves as a way to promote better health, but for the EOL caregiver, these practices can be utilized as a way to cope with ongoing stressors.

Secondary stressors. As a result of caregiving, some caregivers need to make sacrifices or changes to daily routines and activities. Caregivers may find themselves having to juggle between multiple roles as they try to keep up with familial, work, and/or social responsibilities. In addition, some caregivers may be faced with having to make changes in the workforce by reducing work hours and/or taking personal time off to meet the needs of CRs. A reduction in salary, along with additional costs associated with medical expenses and other care needs can place undue financial strains on working caregivers (Grunfeld et al., 2004). These stressors, known as secondary stressors directly emerge from primary stressors and can spread or “proliferate” into other domains of a caregiver’s life (Pearlin et al., 1990). For some caregivers, the ongoing impact of secondary stressors can lead to greater impairments in overall well-being (Haley, 2003; Weitzner et al., 2000).

Caregivers who engage in multiple roles experience difficulties due to restrictions in time, energy, and resources (Goode, 1960, as cited in Kim, Baker, Spillers, & Wellisch, 2006a). Employed females, in particular, have been found to be at a greater risk of experiencing distress. Kim and colleagues found that the cumulative impact of working outside of the home, in addition to having to care for children and a dependent adult posed significant strains to emotional health. Unlike their male counterparts, working female caregivers have been found to experience greater levels of role overload (i.e., feelings of exhaustion and fatigue) (Gaugler et al., 2008a).

Moreover, restrictions or interferences with personal, work, and social activities have also been found to play a significant role in overall mood disturbance among cancer caregivers (Cameron et al., 2002). An interesting finding emerged in this study revealing

that regardless of the level of care provided, greater levels of emotional distress were associated with greater restrictions in lifestyle activities. Implications from this study suggest that engagement in activities outside of the caregiving role can serve as an adaptive way to cope with the caregiving experience. Isolation from normal activities may invoke feelings of entrapment, helplessness, and depression.

Mediating variables. Mediating variables are defined as protective functions or coping resources that mitigate or buffer the effects between stressors and caregiving outcomes (Pearlin et al., 1990; Weitzner et al., 2000). Mediating variables such as social support, spirituality, health, optimism, and positive coping skills can protect the self from physical, emotional, social, and spiritual distress. These internal and external resources play a fundamental role in mediating caregiving outcomes, albeit positive or negative. Differences in the availability and use of coping resources help to account for individual differences, providing some rationalization as to why caregivers may cope differently from one another.

Social support. There is a well established body of research suggesting that social support mediates the effects of stressors on caregiver outcomes (Lim & Zebrack, 2004; Pinquart & Sorensen, 2007). As a resource, social support has been defined as a multidimensional concept that embodies distinct types of functional support (i.e., informational, instrumental, emotional, and esteem support) (Bloom, 2000). Whether caregivers receive tangible assistance, information, or emotional comfort and validation, these types of support lend themselves to feelings of competency, reverence and affection, and a sense of connectedness with others. This protective resource appears to help caregivers cope with the ever-changing demands associated with EOL caregiving.

In general, studies have revealed that feeling connected and engaged with others enhances overall well-being. In a study conducted by Tang (2009), greater levels of both qualitative (i.e., informational and emotional support) and quantitative (i.e., number of support networks) social support enhanced QOL. Perceived satisfaction with formalized, community resources, along with higher levels of perceived social support from family and/or friends has been shown to predict lower levels of caregiver strain (Bainbridge et al., 2009), depression (Gaugler et al., 2009; Haley et al., 2003) and psychological distress (Dumont et al., 2006). Furthermore, greater levels of social support have been associated with fewer health problems, disruptions in daily schedule, and levels of emotional distress (Daly, Douglas, Lipson, & Foley, 2009). These studies reveal that caregivers who feel supported and connected with others are less likely to feel alone and isolated within the caregiving role.

Further, socioemotional support helps to prevent the proliferation of stress into other domains of a caregiver's life. In a study conducted by Gaugler et al. (2008b), social support had a buffering effect as it protected caregivers from perceiving the caregiving role as being emotionally and financially burdensome. Having a strong supportive network also reduced family tension and conflict. Perhaps, in a way, social support boosts confidence and optimism, giving caregivers a sense of hope that they will be able to overcome challenges associated with the caregiving role. If caregivers perceive that they are supported by others, they may be more likely to seek assistance and support during times of need.

Spirituality. Research on the role of spirituality suggests it, too, has a buffering effect between care stressors and caregiver outcomes (Colgrove, Kim, & Thompson,

2007; Fry, 2001; Ka`opua, Gotay, & Boehm, 2007). Spirituality has been characterized as a coping resource because it involves “meaning-centered processes” (Ka`opua et al., 2007) or, in other words, it involves the process of trying to make meaning out of a stressful encounter or event. Within the stress and coping framework, meaning-making is defined as a process of cognitive reappraisal, and plays an essential role in the successful adaptation to a stressful and chronic experience such as EOL caregiving (Folkman, 1997; Gall et al., 2005). If a caregiver is able to find meaning and purpose within the caregiving experience, positive caregiver outcomes should emerge.

In a longitudinal study of caregiving partners of terminally ill patients, Folkman (1997) found spirituality helped caregivers to reappraise their caregiving situation in a positive way, which in turn facilitated adaptive coping and positive psychological states. Meaning-making helped CRs and caregivers to transcend beyond the dying experience, giving them the opportunity to appreciate and value the simple things in life. Similarly, in a qualitative study conducted by Ka`opua et al. (2007), spirituality was reflected in the construction of an “embracing spirit” (p. 36). Spirituality enabled caregivers to find hope amid change and loss; to embark on challenges with compassion; and, to appreciate life to its fullest. Nurturance of this embracing spirit propelled caregivers to engage in adaptive ways of coping that included marriage preservation and the cultivation of couple intimacy; personal growth and learning; health-related attitudes and behaviors aimed at promoting wellness; and, the development and sustainment of meaningful community relationships and support. Moreover, in another study, spirituality was a source of strength that enabled caregivers to overcome various challenges within the caregiving experience (Waldrop, Kramer, Skretny, Milch, & Finn, 2005). For these caregivers,

spirituality facilitated a renewed sense of self that brought about a different way of looking at life and death. This renewed spirit helped to build resiliency as it lessened the effects of care-related stressors on emotional and physical health.

Spirituality has been found to have positive effects on overall well-being in other studies as well. In a study conducted by Colgrove et al. (2007), spirituality helped to protect EOL caregivers from the adverse effects associated with caregiver stress. Caregivers who possessed higher levels of spirituality exhibited better mental health outcomes than those with lower levels. Tang (2009) found that spirituality played a central role in the lives of hospice caregivers. Caregivers who reported higher levels of spiritual well-being were more likely to experience greater QOL. Existential variables such as personal meaning, optimism, and spiritual beliefs and practices emerged as salient predictors on measures of psychological well-being in another study (Fry, 2001). This study revealed that bereaved spouses, widows in particular, still found personal meaning in life despite ongoing negative life events and physical health problems.

For some caregivers, limited spiritual resources or unmet spiritual needs can exacerbate and/or lead to impairments in emotional well-being. For example, Buck and McMillan (2008) found a positive correlation between unmet spiritual needs and caregiver depression among EOL caregivers. Particularly, an increase in unmet spiritual needs resulted in increases in depressive symptoms. In this study, the most commonly reported unmet needs included the need to be with family and friends, the need to laugh, think happy thoughts, and see others around them smile. These needs appear to underscore the importance of promoting social and emotional connectiveness with others.

In another study, spiritual needs encompassed psychological, physical, and social domains (Murray, Kendall, Boyd, Worth, & Benton, 2004). Care recipients and their caregivers appeared to experience similar spiritual needs during the disease trajectory. Commonly expressed emotions included feelings of despair, shock, uncertainty, uselessness, and depression. These emotions often reflected existential needs such as the need to find meaning and purpose within the disease and caregiving context. Dyads also counterbalanced such emotions by expressing hope and positive thinking. Feeling connected to others and relying on activities that provided comfort or inner peace helped CRs and caregivers to cope with spiritual issues and needs.

The aforementioned studies suggest that the role of spirituality is an invaluable inner resource that strengthens and empowers caregivers to turn to adaptive ways to cope in the midst of their loved ones' impending deaths. It is also an important coping resource to rely on when searching for meaning even in times of suffering. However, when spiritual needs are unmet, emotional and spiritual suffering may result. Caregivers may find themselves not only struggling with ways to adapt and manage stress but also in finding personal meaning within the caregiving role.

Stress outcomes. Stress outcomes are defined as the consequences that result from primary and/or secondary stressors (Pearlin et al., 1990; Weitzner et al., 2000). In caregiving studies, outcome measures assess physical, emotional, social, and spiritual functioning. Commonly documented outcome measures include depression (Doorenbos et al., 2007; Haley et al., 2001; Nijboer et al., 1999); psychological and emotional distress (Cameron et al., 2002; Matthews et al., 2004); caregiver strain and burden (Bainbridge et al., 2009); and QOL (Matthews et al., 2004; Nijboer et al., 1999; Tang, 2009). Although

positive outcomes have not been extensively studied, it appears that more caregiving studies are beginning to focus on the positive aspects of the caregiving experience (Haley et al., 2001; Matthews et al., 2004).

Limitations of Previous Research

Over the last decade, the caregiving field has seen a profusion of research in the area of EOL and cancer caregiving. The development of Pearlin et al.'s (1990) stress process model of caregiving initiated a new way for researchers to examine the caregiving experience. Over time, the original model has been modified and tested, proving to be useful in generating new knowledge to the field as well as in advancing clinical practice. However, previous research has been limited due to sampling approaches, sample size, design, and the limited selection of variables included in these models. These limitations have posed threats to internal and external validity in previous research studies. Although the aforementioned limitations are due to feasibility issues surrounding EOL and cancer caregiving research, such limitations are worth noting in order to influence the direction of future studies.

Selection of variables. Various researchers have stressed the importance of examining an array of variables within the stress process model (Gaugler et al., 2005; Nijboer et al, 1999). For instance, Raveis et al. (1999) stressed the importance of considering environmental or situational factors within the caregiving experience. Cameron and colleagues (2002) noted the importance of examining the role of mediating variables within the model. Pearlin et al. (1990) described the need to examine “the relationship among the many conditions leading to personal stress” in order to gain a richer understanding of the “manifestations of stress” (p. 585). Although stress process

models are designed to examine various dimensions within the caregiving experience, Bainbridge and colleagues (2009) view this undertaking as a challenging and “daunting task” (p.543), particularly since there is a risk of inducing burden on research participants, especially when using multiple scales to tap into the various domains that encapsulate the stress process.

As a result of such challenges, researchers have noted the difficulties or limitations of testing multiple variables within their models (Doorenbos et al., 2007; Kim et al., 2007). This appears to be an even greater challenge in EOL care research. The need to engage in ethical and sensitive research is highly warranted with this vulnerable population. Although it is unrealistic to include an exorbitant number of variables to the model, researchers should strive to incorporate “a mix of circumstances, experiences, responses, and resources” (Pearlin et al., 1990, p. 591), in addition to balancing the risks and benefits associated with EOL care research. This study incorporated a wide range of variables.

Sampling and sample size. Due to the population of interest, the majority of studies utilized non-probability sampling approaches. Convenience sampling appeared to be the approach chosen by most researchers (Dumont et al., 2006; Matthews et al., 2004; Ussher & Sandoval, 2008). Although there are clear advantages of using non-probability sampling approaches (i.e., time, access to participants, cost), this approach lends itself to sampling bias and unrepresentative samples. For the most part, researchers acknowledged this limitation. Study populations were often homogenous in nature, lacking diversity along an array of sociodemographic characteristics. For instance, a majority of studies included samples which were mostly white (Chentsova-Dutton et al.,

2002; Haley et al., 2003; Kim et al., 2007, 2006b; Matthews et al., 2003; Northouse et al., 2000); of a higher socioeconomic background (Kim et al., 2006b; Matthews et al.); and with female spouses (Andrews, 2001; Gaugler et al., 2005; Redinbaugh et al., 2003). These findings are particularly salient for the field of social work. The lack of diversity in these studies point to the need to examine more heterogeneous samples.

Some studies were also limited due to the sample characteristics of the study sample. For instance, in these studies, participants appeared to be more functional and healthier (e.g., Hagedoorn et al. 2002; Matthews et al., 2003) as opposed to being bedbound and in poorer health. The inclusion of poorer functioning patients can be reflected in lower response rates and sample attrition in other studies as well (Grunfeld et al., 2004; Kim et al., 2007; Nijboer et al., 2001). Because it is unknown how truly representative these samples are to the larger population of interest, generalizability is limited.

Another limitation in some of these studies is the small sample size. Smaller samples were primarily found in EOL studies of hospice and palliative care patients (e.g., Andrews, 2001; Bainbridge et al., 2009; Carrion, 2010; Chentsova-Dutton et al., 2002; Haley et al., 2003, 2001; Jo et al., 2007). Smaller samples reduce the likelihood of obtaining representative samples, thus limiting generalizability. Further, small sample sizes limit the ability to detect true relationships among variables, which increases the chance of making Type II errors or poor sensitivity of finding significant results (Rubin & Babbie, 2011). This study incorporated the EOL experiences from a large sample of hospice patients and caregivers.

Design. Finally, the majority of the aforementioned studies were cross-sectional (e.g., Gaugler et al., 2008a; Haley et al., 2003; Matthews et al., 2003). As with any research that utilizes this approach, causal interpretations cannot be made. However, one way to counterbalance this limitation is through replication (Rubin & Babbie, 2011). By building on existing research, this study helped to increase the generalizability of previous research findings.

CHAPTER 3:

METHODS

This chapter presents an overview of the conceptual model that was used to examine the EOL caregiving experience among hospice caregivers. Research questions and hypotheses are reviewed. A detailed description of the data source, sample, data collection procedures, and instruments follow. The chapter concludes with ethical considerations and data analysis steps.

Utility of the Stress Process Model of Caregiving

Based on previous research, the utility of the stress process model of caregiving offers a comprehensive way to better understand the caregiving experience (Bainbridge et al., 2009; Doorenbos et al., 2007; Haley et al., 2003; Matthews et al., 2003). In general, the model offers a holistic way of examining how risk factors can perpetuate stress, as well as how certain protective factors can protect against it. In other words, the model examines how primary and secondary stressors can impact the caregiving experience, and how resources mediate the relationship between stressors and caregiver outcomes. The model also incorporates the influence of sociodemographic variables, thus enabling researchers and practitioners to identify groups that may be at a greater risk of experiencing caregiver stress (e.g., depression).

Modified Stress Process Model of Hospice Caregiving

The stress process model of caregiving (Pearlin et al., 1990) was modified to identify the best fit predictive model of caregiver depression among hospice caregivers of terminally ill cancer patients. Figure 2 displays both theoretical and empirically tested variables that were included in the model.

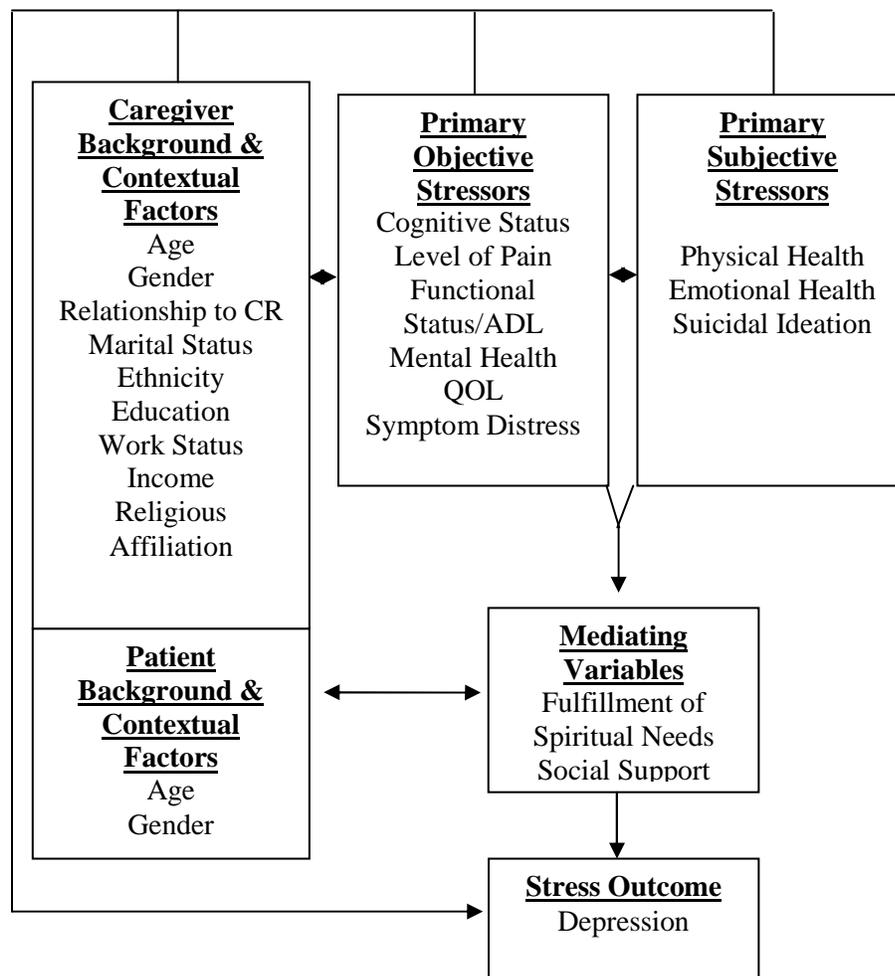


Figure 3. Stress Process Model of Hospice Caregiving.

Research Questions and Hypotheses

The following research questions and hypotheses were tested:

1. What is the relationship between caregiver depression and sociodemographic characteristics of CRs and caregivers? *It is hypothesized that gender, age, relationship to the CR, and work status is associated with caregiver depression. Specifically, women will experience greater levels of depression than men. Younger, working females will experience higher levels of depression than younger and/or older, non-working females. Adult daughters and wives will experience higher levels of depression than other caregivers. In addition, it is hypothesized that the patient's gender and age will be associated with caregiver depression.*
2. What is the relationship between caregiver depression and primary objective stressors? *It is hypothesized that higher levels of patient symptomatology is negatively associated with caregiver depression. Caregivers of patients who present with poorer QOL and who have lower cognitive and functional statuses will exhibit more depressive symptoms than caregivers of patients with better QOL and cognitive and functional statuses. In addition, caregivers of patients who report being in pain and having higher levels of depressive and symptom distress scores will experience more depressive symptoms than caregivers of patients in better mental and physical health.*
3. What is the relationship between caregiver depression and primary subjective stressors? *It is hypothesized that poorer emotional and physical health will be positively correlated with caregiver depression. Specifically, caregivers who report being in poor physical and/or emotional health will experience greater levels of depression than caregivers who perceive their physical and/or emotional health as being strained or*

taxed. Also, there will be a positive relationship between suicidal ideation and depression. Caregivers presenting with suicidal thoughts will more likely be depressed.

4. What are the best predictors in identifying caregiver depression among hospice caregivers? *The best fit predictive model will include an array of variables, with primary subjective stressors (e.g., emotional and physical health) contributing the most unique variance to the model.*

5. Do certain resources (e.g., social support and fulfillment of spiritual needs) mediate the relationship between caregiver depression and sociodemographic characteristics, primary objective stressors, and primary subjective stressors? *It is hypothesized that caregivers with greater levels of social support and fewer unmet spiritual needs will experience less depressive symptoms than caregivers who have lower levels of support and more unmet spiritual needs.*

Data Source

This study used a secondary dataset from a National Institutes of Health funded grant titled “Systematic Assessment to Improve Hospice Outcomes” (McMillan, RO1 NR008252). The primary aim of the original study was to examine the efficacy of reporting systematic data from standardized patient and caregiver assessment measures to hospice staff during regularly scheduled interdisciplinary team meetings (IDTs). Utilizing an experimental design, hospice sites were randomly assigned to either continue with normal reporting practices (control group) or receive an enhanced patient-caregiver report from additional standardized assessment measures (experimental group). It was expected that patient-caregiver dyads who were under the care of staff members from the

experimental teams would experience fewer physical, emotional, and spiritual problems than those dyads under the care of control teams.

Data were collected over 30 months (2004-2009) by experienced hospice nurses and social workers. This author was a member of the research team that collected data from one of the hospice sites. A series of valid and reliable standardized assessments measures were collected from hospice patients and caregivers at three points in time: baseline (1-3 days after admission to hospice), Time 2 (8-12 days after the first IDT meeting), and Time 3 (15-19 days after the second IDT meeting). Oral and written reports were delivered to experimental teams shortly after admission and then again approximately one week after the first IDT meeting. This study only examined baseline data.

The aforementioned secondary dataset was used for several reasons. First and foremost, the dataset includes a wide range of standardized assessment measures that examined physical, psychological, social, and spiritual domains of both patients and caregivers. Therefore, the use of this dataset allowed for a meaningful investigation of how biopsychosocial-spiritual variables impacted the emotional health of caregivers. Second, the dataset is based on a large sample of hospice patients and caregivers. Because EOL care research is often difficult to conduct, smaller samples are often recruited which limits the generalizability of research findings. The funding for the larger study enabled investigators to recruit a larger sample size over the 4-year funding period which helped to reduce sampling error. As Rubin and Babbie (2011) point out, well-funded studies have the advantage of being “methodologically strong,” reflecting better controlled designs and stronger measurement procedures (p. 412). Third, this

dataset was chosen because of this author's familiarity with the research protocol, consent process, sampling and recruitment strategies, data collection procedures, and ongoing access to the study principal investigator. As part of the research team, this author has firsthand knowledge about the quality of the data. Data were collected in a systematic and rigorous manner to ensure that measures were accurate and complete and that research protocols were followed during the data collection process to avoid systematic error.

Sample

Setting. Participants were recruited from two large non-profit hospices in southwest Florida. Both hospices provided similar interdisciplinary services to rural, urban, and suburban patients and their caregivers. Average length of stay, annual hospice admissions, diagnoses, payment source, and basic patient demographics were comparable across hospice sites (McMillan, 2001).

Participants. Sample participants included patient and caregiver dyads who were at least 18 years of age, able to read and speak English, and who voluntarily consented to participate in the study. Further inclusion screening criteria for patients included having a cancer diagnosis and an identifiable caregiver who provided at least 4 hours of daily care. Patients were excluded if they were actively dying, had a functional score of 30 or less as measured by the Palliative Performance Scale (PPS), or were confused as indicated by the Short Portable Mental Status Questionnaire (SPMSQ). Caregivers were excluded from the study if they were actively seeking cancer treatment or were confused. A total of 717 patient-caregiver dyads made up the sample size in this study.

Procedures

Data collection. A purposive sampling approach was used to recruit patient-caregiver dyads for the original study. Research assistants (RAs) retrieved a daily admission report from selected hospice sites. Inclusion and exclusion criteria were reviewed for each patient admitted to hospice to ensure eligibility. After the initial screening, RAs phoned eligible participants to explain the study and to obtain verbal consent to come to the home if dyads were interested in participating.

Once verbal consent was obtained, RAs scheduled home visits within 24 to 72 hours after hospice admission to review the study, obtain written informed consent, and to further screen participants to ensure eligibility. A series of assessment measures were then given to the patient and caregiver. Research assistants separated participants to ensure privacy and independent completion of the data. The nursing RA accompanied the patient, while the social worker RA accompanied the caregiver. These interviews took approximately 20-30 minutes to complete. After participants completed the measures, they were asked if they would be willing to complete the assessments one week later. Two additional home visits were made if participants agreed to continue in the study. In order to ensure that measures were accurate and complete, RAs checked each assessment measure prior to leaving the participants' homes.

Instruments

A series of baseline measures were completed by both patients and caregivers. These measures are described and outlined within the domains of the stress process model. Each measure is included in the attached Appendices (Appendix A-M).

Caregiver and Patient Background Factors

Sociodemographic variables. Basic demographic data were collected from both patients and caregivers (Appendices A and B). Demographic variables included age (in years), gender (0 = male, 1 = female), relationship to the patient/caregiver (1 = spouse/significant other, 2 = parent, 3 = adult child, 4 = siblings/other), marital status (0 = not married, 1 = married), ethnicity (0 = non-white, 1 = white), educational level (in years), employment status (e.g., retired, 0 = no, 1 = yes) income (in dollars), and religious affiliation (1 = Christian background, 2 = spiritual, 3 = none).

Primary Objective Stressors

Cognitive functioning. Cognitive impairment is broadly defined as a clinical syndrome marked by a measurable decline in memory or other cognitive abilities which can lead to further cognitive deficits and impairments in overall functioning (Rosenberg, Johnston, & Lyketsos, 2006). The Short Portable Mental Status Questionnaire (SPMSQ) is a 10-item screening tool that assesses cognitive impairment among institutionalized and community dwelling adults (Pfeiffer, 1975) (Appendix C). Scores range from 0 to 10, with lower scores indicating greater levels of cognitive impairment. In the original study, the restricted range fell between 8 and 10. Patients and caregivers who scored at or below 7 were excluded from the study. Four week test-retest reliability coefficients have been found to range from 0.81 to 0.85, while the scale's sensitivity and specificity for detecting mild to severe levels of cognitive impairment is mixed (McDowell, 2006).

Activities of daily living. Activities of daily living (ADLs) are operationalized as the ability to independently care for oneself in daily activities of bathing, dressing, toileting, transferring, continence, and feeding (Katz, Ford, Moskowitz, Jackson, & Jaffe,

1963). Research assistants assessed the patient's level of independence or dependence among six functions of daily living using the Activities of Daily Living Index (ADLI) (Appendix D). Scores are ranked on a seven-point scale with "A" indicating complete independence and "G" indicating complete dependence. Research provides evidence of content, concurrent, and predictive validity (Brorsson & Asberg, 1984; Hamrin & Lindmark, 1988; Law & Letts, 1989). A high degree of internal consistency has also been documented ($\alpha = 0.87$ and 0.94) (Wallace & Shelkey, 2008). In this study, reliability for the scale was good ($\alpha = 0.85$).

Functional status. Palliative performance is operationally defined as the level of functionality among patients (Campos et al., 2009). The Palliative Performance Status (PPS) measure assesses five domains of a patient's physical status—ambulation, activity level as evidence of disease, self-care, food/fluid intake, and level of consciousness (Anderson, Downing, Hill, Casorso, & Lerch, 1996) (Appendix E). Theoretical scores range from 0% (death) to 100% (normal activity). In the original study, patients were required to score at or above 40, thereby restricting the range of scores from 40% to 100%. The scale has been found to be a good predictor of mortality among early-stage cancer patients, nursing home residents, and hospice patients with non-cancer diagnoses (Harrold et al., 2005). The PPS also has good inter-rater reliability ($\alpha = 0.91$) (Campos et al., 2009).

Pain. Pain is operationally defined as the degree of discomfort in one or more areas of the body as perceived by an individual. The short-form, Brief Pain Inventory (BPI) was administered to patients (Daut, Cleeland, & Flanery, 1983) (Appendix F). This instrument measures the intensity of pain on a scale of 0-10, with 10 being the worst

possible pain. A body diagram is used to assist the patient in locating areas of pain. Patients are asked to describe pain symptoms, alleviating factors that relieve pain including the use of medication, and aggravating factors that are perceived to induce pain. The BPI has been found to be a valid and reliable measure in assessing pain among cancer patients (Tittle, McMillan, & Hagan, 2003). Tittle and colleagues found the BPI to correlate well with the visual analog scale (VAS), providing support for criterion validity ($\alpha = 0.71$ and 0.73). The Pain Interference Subscale of the BPI was found to have excellent reliability ($\alpha = 0.95$ and 0.97). A single item question from the short-form BPI was used to assess the presence or absence of pain in this study.

Symptom distress. Symptom distress is operationally defined as the degree of physical or emotional anguish experienced from a specific symptom(s) (Rhodes, McDaniel, & Matthews, 1998). The Memorial Symptom Assessment Scale (MSAS) assesses physical and psychological symptoms commonly associated with cancer (Portenoy et al., 1994). Patients completed a revised, 25-item scale to assess the level of severity and distress of cancer symptoms (Appendix G). Patients rate the level of distress and severity of each symptom using a 5-point Likert-type scale which ranges from 0 (i.e., symptom is not severe and/or not distressful) to 4 (i.e., symptom is very severe and/or very distressful). Subscale scores are summed and result in a total distress and severity score which ranges from 0 to 100, with higher scores indicating greater distress and/or severity. The revised MSAS has good psychometric properties. The scales have adequate internal consistency ($\alpha = 0.73 - 0.74$). A significant correlation between the MSAS distress scores and the Hospice Quality of Life Index (HQLI-28) scores ($r = -0.67$,

$p < .001$) provide evidence for construct validity (McMillan & Small, 2002). Reliability for the total distress and severity subscales in this study were good ($\alpha = 0.83-0.85$).

Quality of life. Quality of life (QOL) is operationalized as a subjective, multidimensional concept that encompasses the physical, psychological, social, and spiritual aspects of overall well-being (McMillan & Weitzner, 1998). Patients completed the Hospice Quality of Life Index-14 (HQLI-14), a shortened version of the 28-item HQLI that was originally developed by McMillan and Weitzner (1998) (Appendix H). The scale assesses overall QOL across psycho-physiological, functional, and social-spiritual domains. Individual items are scored on a 0 to 10 scale. Higher scores reflect a more favorable response. Items are then summed, with total scores ranging from 0 (worst QOL) to 140 (best QOL). The HQLI-14 has been shown to have adequate internal consistency and excellent concurrent validity with the original 28-item measure (S. C. McMillan, personal communication, July 12, 2010). In this study, the scale had adequate internal consistency ($\alpha = 0.72$).

Primary Subjective Stressors

Emotional and physical health. Health status is operationalized as the level of functioning among physical and mental dimensions of health. The 36-item Short Form Health Survey (SF-36) is a valid and reliable measure that has been widely used to assess health status (McHorney, Ware, & Raczek, 1993; Ware, 2000). The instrument captures two dimensions of health, physical health and mental health. A shorter, 12-item version of the SF-36 has been developed to reduce response burden (Ware, Kosinski, & Keller, 1996). The SF-12 reflects the same eight health domains that form the physical component summary (PCS) and the mental component summary (MCS) subscales in the

SF-36 (Appendix I). A total score is calculated for both the PCS-12 and MCS-12 scales, with higher scores indicating better health. In the general population, both scales have a mean of 50 and a standard deviation of 10. Relatively high correlations exist between the PCS and MCS components of the SF-12 and SF-36 scales ($r = 0.95$ and 0.97 , respectively) which suggests that the shorter scale is a valid and reliable tool for measuring health status (Ware et al., 1996). Strong psychometric properties for the SF-12 have been found in other studies (Singh, Gnanalingham, Casey, & Crockard, 2006; Ware et al., 1996).

Suicidal ideation. Suicidal ideation is operationally defined as thinking about death and/or harming oneself. A single item question from the Structured Clinical Interview for Depression (SCID-I-RV) was used to assess suicidal risk in patients and caregivers (Appendix J). The SCID-I-RV is a semi-structured interview used by clinicians to make an Axis I, DSM-IV diagnosis. In general, the SCID has adequate psychometric properties (Biometric Research, 2010).

Mediating Variables

Social support. Social support is operationally defined as the perceived level of satisfaction with informal and formal types of care. Social support was assessed using three items from Krause and Borawski-Clark's (1995) multidimensional social support scale (Appendix K). Caregivers rated their levels of satisfaction with tangible, emotional, and informational forms of support using a four point Likert-type scale ranging from 1 (not at all satisfied) to 4 (very satisfied). Items are summed and scores range from 3 to 12, with lower scores indicating little to no satisfaction. The measure has adequate internal consistency ($\alpha = 0.68, 0.69$) (Jang, Haley, Small, & Mortimer, 2002; Krause &

Borawski-Clark, 1995). In this study, the alpha coefficient for the three item scale approached an acceptable range for a shortened scale ($\alpha = 0.66$).

Spiritual needs. Spiritual needs are operationally defined as something that is required or needed in order for an individual to find meaning and purpose in life (Hermann, 2006). Patients and caregivers completed the 17-item Spiritual Needs Inventory (SNI) to assess their spiritual needs (Appendix L). The scale is divided into two parts. In part B, spiritual needs that are deemed as “important in order to live life fully” are scored on a five point Likert-type scale with scores ranging from 1 (never) to 5 (always). These scores are summed and range from 17 to 85. Higher scores indicate greater spiritual needs. In part C, participants indicate whether their spiritual needs are being met by indicating yes or no. Unmet spiritual needs can be summed by calculating the number of no responses. Factor analysis confirmed that the SNI is comprised of five factors or subscales (e.g., outlook, inspiration, spiritual activities, religion, and community). Psychometric properties for the scale are acceptable. The subscales have adequate internal consistency (alpha ranges from 0.62 to 0.78), while the coefficient alpha for the total scale indicates good reliability ($\alpha = 0.85$). Correlations between the SNI and the Cantril ladder (e.g., life satisfaction) scale ($r = -0.17$) provides some preliminary, albeit weak evidence for construct validity (Hermann, 2006). Reliability for the SNI in this study was good ($\alpha = 0.86$).

Outcome Variable

Depression. Depression is operationally defined as an emotional state that presents with loss of interest or pleasure, low energy, and feelings of sadness, helplessness, and low self-worth (World Health Organization [WHO], 2010). The Center

for Epidemiological Studies Depression Scale (CES-D) is a 20-item multiple choice measure that has been widely used to assess late life depression (Radloff, 1977). The CES-D is a reliable and valid measure for use in the identification of depressive symptoms across a wide range of populations (Radloff & Terri, 1986). In the original study, a simpler, shorter version of the CES-D was administered to both patients and caregivers (Appendix M). This shorter scale has been developed for specific use with older adults to reduce response burden (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993). Using a dichotomous response set, participants indicate either the presence or absence of individual depressive symptoms. Items are summed and a score of 4 or greater is indicative of significant depressive symptomatology. Psychometric properties of the 10-item scale indicate excellent internal consistency ($\alpha = 0.92$) and good test-retest reliability ($r = 0.83$). The scale has also excellent criterion validity as indicated in the sensitivity, specificity, and positive predictive values which were 97%, 84%, and 85% respectively (Irwin, Artin, & Oxman, 1999). A high correlation ($r = 0.88$) between the original and shorter scale suggests that the modified version is an acceptable screening tool for the identification of depressive symptoms (Kohout et al., 1993). In this study, Cronbach's alpha was 0.71, thus suggesting that the items have adequate internal consistency.

Ethical Considerations

The Bioethics Committees of the Hospices and the Institutional Review Board for the Protection of Human Subjects from the University of South Florida (USF) approved the original study. In addition, strict adherence to ethical standards and guidelines were enforced by RAs to safeguard participants from emotional distress. Prior to

administering the assessment measures, RAs informed participants that their participation was completely voluntary and would not interfere with hospice services. Participants were also informed of the possible risks (i.e., emotional distress) from participating and the right to withdraw from the study without penalty (e.g., disruptions in services). Research assistants made every attempt to ensure that participants understood their rights and what was being asked of them. They were available to answer any questions before, during, and after the study. Special precautions were also taken during the administration of the assessments measures. The interview process was stopped if participants requested to withdraw or if there were apparent signs of emotional or physical distress.

Because this study used de-identified secondary data, there was no risk to human participants. The original data is stored and locked in cabinets at the USF. A separate baseline, de-identified dataset was created for the purposes of this study.

Data Analysis

As various researchers have pointed out, the use of secondary data should be cautiously evaluated in order to ensure that studies are contributing to science in a meaningful way as opposed to haphazardly studying something simply because data are available (Drake & McHugo, 2003; Huston & Naylor, 1996). Therefore, in order to ensure that this secondary dataset met minimum standards to test the proposed research questions, preliminary analyses of the data were conducted. In summary, it was demonstrated that the quality of the data was sufficient. For instance, variables mapped onto the conceptual framework; the dataset had sufficient statistical power, contained relatively little missing data, and the variance of the data was adequate; selected measures had good psychometric properties; there was an adequate degree of congruence between

the way variables were conceptualized and operationalized, thus providing support to suggest that appropriate instruments were used to measure the constructs in the study; and, preliminary testing of the data revealed that the theoretical variables were related, to some extent, to the dependent variable. A complete description of these findings can be found in Appendix N.

Descriptive statistics were conducted to examine measures of central tendency and measures of dispersion for all variables. Missing data and outliers were assessed via the use of frequency distributions, histograms, and box plots. Univariate normality was assessed by examining skewness and kurtosis coefficients. Bivariate analyses were then conducted to examine the relationship between demographic, stress-related variables (primary objective and primary subjective), mediating variables (social support and fulfillment of spiritual needs), and the dependent variable (caregiver depression). Pearson's product-moment correlation was used to examine the relationship among continuous variables and one-way analysis of variance (ANOVA) was used for nominal level data. A series of bivariate scatterplots were conducted to examine the degree of linearity and homoscedasticity among continuous variables.

Hierarchical multiple regression analysis was conducted to develop the best fit predictive model for caregiver depression among hospice caregivers. In order to establish parsimony, only variables significant ($p < .05$) to the dependent variable were entered into the multivariate regression model. Categorical variables that were found to have a significant relationship with the dependent variable were transformed into dummy variables prior to entering them into the model. Variables were entered in sequential blocks to reflect the domains of the stress process model in the following order: (1)

caregiver demographic variables, (2) patient demographic variables, (3) primary objective stressors, (4) primary subjective stressors, and (5) mediators. Residual scatterplots were assessed to test for multivariate normality, linearity, and homogeneity. Multicollinearity was assessed by examining the variance inflation factors (VIFs) and tolerance statistics (e.g., VIF values ≥ 10 or tolerance values ≤ 0.1 indicates multicollinearity) (Mertler & Vannatta, 2005).

Baron and Kenny's (1986) guidelines for testing mediation effects was used to examine the influence of the mediators on the dependent variable. Specifically, the following steps were taken to determine (1) the relationship between the independent variables and the dependent variable, (2) the relationship between the independent variables and the mediating variables, and (3) the relationship between the mediators and the dependent variable. If a nonsignificant relationship was found in steps 2 or 3, this provided evidence to conclude that mediation was unlikely and that no further testing was needed. If a significant, bivariate relationship was found in steps 2 or 3 this provided support to proceed to the final step—testing for mediation.

In step four, a series of regression models were created to examine the relationship between the independent variables and dependent variable when controlling for the mediating variables. If the direct relationship between the independent variables and the dependent variable reduced in strength or became non-significant, it was concluded that either partial or complete mediation was present (Baron & Kenny, 1986). Mediation effects were further analyzed using the Aroian adjustment version of the Sobel test (MacKinnon, Fairchild, & Fritz, 2007). This test provides statistical evidence ($p < 0.05$) to support the indirect effect of a mediator (i.e., degree of reduction or change

in the regression coefficients), and is also viewed as an appropriate mediational test to use with the Baron and Kenny (1986) framework (Preacher & Leonardelli, 2010). Version 18.0 of the Statistical Package for the Social Sciences (SPSS; SPSS Inc, Chicago, IL) was used to conduct the aforementioned statistics.

CHAPTER 4:

RESULTS

This chapter presents the results of the study. First, sociodemographic characteristics of the study sample are described. Next, univariate, bivariate, and multivariate results are presented to answer the proposed research questions described in Chapter 3. Specifically, results outline the risk and protective factors that were predictive of caregiver depression among older hospice caregivers.

Sample Characteristics

Hospice patients were predominately white (96.9%), married (63.6%), and men (56.3%). Most patients were elderly ($M = 72.7$, $SD = 12.1$) and cared for by their spouses (66.2%). Common cancer diagnoses included lung cancer (34%), pancreatic cancer (9.2%), and colon cancer (7.2%). Patients required minimal to moderate levels of assistance with ADLs as evidenced by ADL ($M = 2.5$, $SD = 2.2$) and PPS scores ($M = 57.1$, $SD = 10.9$). The mean symptom distress score was 20.5 ($SD = 14.1$). Patients reported having an average of 3.0 ($SD = 2.2$) depressive symptoms. Quality of life scores ranged from 52 to 140, with a mean score of 102.2 ($SD = 17.4$) (Table 4.1).

The majority of caregivers were white (95.8%) and female (73.6%). The mean caregiver age was 65.4 years ($SD = 13.7$). The mean level of education was 13.2 years ($SD = 2.7$). Thirty-six percent of caregivers reported incomes lower than \$30,000. Most

caregivers were retired (59.8%) and did not rely on others to help with caregiving needs and responsibilities (60.3%). Caregivers were generally satisfied with the amount of support received from others ($M = 10.8, SD = 1.7$). The mean number of unmet spiritual needs was low ($M = 1.3, SD = 2.1$). On average, caregivers reported being in “good” physical health and had a mean of 2.9 ($SD = 2.2$) depressive symptoms. However, nearly 20% of caregivers reported being in “fair” to “poor” health, and 37.3% had four or more depressive symptoms. Although the majority of caregivers did not report suicidal ideation, 3.3% reported having suicidal thoughts that ranged from “slight” (e.g., occasional thoughts) to “severe” (e.g., constant thoughts) (Table 4.2).

Table 4.1

Sample Characteristics of Patients: Categorical and Continuous Variables

Patient characteristics	Frequency (n)	Percent (%)	
Gender – Male	400	56.3	
Female	311	43.7	
Race/Ethnicity			
White	690	96.9	
African American	11	1.5	
Hispanic	7	1.0	
Other	4	0.5	
Marital status			
Married	451	63.6	
Widowed	131	18.5	
Divorced	82	11.6	
Separated	8	1.1	
Never married	37	5.2	
Diagnosis			
Lung cancer	241	34.0	
Pancreatic cancer	65	9.2	
Colon cancer	51	7.2	
Prostate cancer	42	5.9	
Breast cancer	40	5.6	
Presence of pain (yes)	526	75.6	
	M	SD	Range
Age	72.7	12.1	21-95
Cognitive status (SPMSQ)	9.2	0.9	7-10
Activities of daily living (ADLI)	2.5	2.2	0-8
Functional status (PPS)	57.1	10.9	40-100
Depression (CES-D)	3.0	2.2	0-9
QOL (HQLI-14)	102.2	17.4	52-140
Symptom distress (MSAS)	20.5	14.1	0-78

Table 4.2

Sample Characteristics of Caregivers: Categorical and Continuous Variables

Caregiver characteristics	Frequency (n)	Percent (%)	
Gender – Female	528	73.6	
Male	189	26.4	
Race/Ethnicity			
White	687	95.8	
African American	10	1.4	
Hispanic	10	1.4	
Other	10	1.4	
Marital status			
Married	554	77.5	
Widowed	54	7.6	
Divorced	68	9.5	
Separated	5	0.7	
Never married	34	4.8	
Relationship to patient			
Spouse/significant other	475	66.2	
Parent(s)	20	2.8	
Adult children	136	19.0	
Siblings/others	86	12.0	
Work status			
Working full time	115	16.1	
Working part time	51	7.1	
Not employed-disabled	34	4.7	
Not employed-retired	428	59.8	
Received help from others (yes)	285	39.7	
1 caregiver	159	22.2	
2 caregivers	53	7.4	
3+ caregivers	62	8.7	
Income			
Low (\leq \$30K)	259	36.1	
Middle ($>$ \$30K to $<$ \$70K)	229	31.9	
High ($>$ \$70K+)	65	9.1	
Religion			
Christian background	561	84.7	
Spiritual	7	1.1	
None	94	14.2	
Suicidal ideation (no)	693	96.7	
(yes)	24	3.3	
	<i>M</i>	<i>SD</i>	Range
Age	65.4	13.7	19-97
Education	13.2	2.7	5-27
Physical health (PCS)	48.5	11.5	13-65
Emotional health (MCS)	46.7	9.7	13-67
Unmet spiritual needs (SNI)	1.3	2.1	0-12
Social support	10.8	1.7	3-12
Depression (CES-D)	2.9	2.2	0-10

Univariate and Bivariate Findings among Stress Process Domains

Univariate analysis of variance (ANOVA) and bivariate correlations were conducted to examine the relationship between caregiver depression and sociodemographics characteristics of caregivers and patients, primary objective and subjective stressors, and mediating variables. Results from each research question are presented.

Research question #1. *What is the relationship between caregiver depression and sociodemographic characteristics of CRs and caregivers?* Several sociodemographic characteristics were associated with caregiver depression. In particular, caregivers who were spouses and in poor health were more likely to report depressive symptoms, ($r = .11, p < .01$ and $r = -.13, p < .001$, respectively). Caregivers with lower educational and income statuses and who were unemployed and/or unable to work because of a disability were also identified as being at risk, ($r = -.08, p < .05$ and $r = .08, p < .05$; $r = -.10, p < .01$ and $r = .13, p < .001$, respectively) (Table 4.3). In addition, univariate analysis of variance revealed a statistically significant difference across relationship type to the patient for caregiver depression, ($F [3, 707] = 9.2, p < 0.001$). Tukey's HSD post hoc test revealed that, in general, siblings who assumed the caregiving role fared better than other caregivers. These caregivers reported the fewest depressive symptoms ($M = 1.8, SD = 1.8$) compared to adult children ($M = 2.9, SD = 2.2$), spouses ($M = 3.1, SD = 2.1$), and parents ($M = 3.4, SD = 2.4$).

Age was the only patient sociodemographic characteristic associated with caregiver depression. Pearson's product-moment correlation revealed that caregivers who provided care to younger patients reported more depressive symptoms than

caregivers of older patients ($r = -.12, p < 0.01$) There was no association between patient gender and caregiver depression (Table 4.3).

Research question #2. *What is the relationship between caregiver depression and primary objective stressors?* Primary objective stressors included patient symptoms such as cognitive status, QOL, presence of pain, symptom distress, depressive symptoms, and ADL. All of these primary objective stressors had a significant, but weak relationship with caregiver depression (Table 4.3). Caregiver depression was negatively associated with the patient's cognitive status ($r = -.08, p < 0.05$) and QOL ($r = -.08, p < 0.05$). In other words, caregivers reported more depressive symptoms when CRs experienced mild cognitive impairment and poorer QOL. Caregiver depression was also related to pain ($r = .08, p < 0.05$), symptom distress ($r = .10, p < 0.01$), depressive symptoms ($r = .08, p < 0.05$), and ADL ($r = .09, p < 0.05$) scores. Specifically, caregivers were more likely to report depressive symptoms when patients presented with pain and depression, needed greater assistance with ADLs, and experienced a higher number of cancer-related symptoms that were perceived by the caregiver to cause distress in the patients.

Research question #3. *What is the relationship between caregiver depression and primary subjective stressors?* Primary subjective stressors included the caregivers' perceptions of their physical and emotional health (including suicidal ideation). Of all of the variables within the stress process model, primary subjective stressors proved to have the strongest correlations with the outcome variable. Caregivers who perceived their emotional health and physical health as being strained were more likely to experience depressive symptoms ($r = -.59, p < .001$ and $r = -.13, p < .001$, respectively). In addition,

caregivers who had thoughts of suicide were also more likely to report greater depressive symptoms than caregivers without suicidal ideation ($r = .21, p < .001$) (Table 4.3).

Table 4.3

Stress Process Variables Correlated with CES-D, Social Support, and SNI Scores

Stress Process Model Variable	Correlation with CES-D	Correlation with Social Support	Correlation with SNI
Block 1 (Caregiver background and contextual factors)			
Relationship			
Spouses	.11**	.05	.07
Adult child	.01	-.12**	.01
Work status			
Not working, nor retired	-.10**	.12***	-.09*
Not working, disabled	.13***	-.01	.07
Educational status (years)	-.08*	-.01	-.05
Income			
Lower	.08*	-.02	.00
Block 2 (Patient background and contextual factors)			
Patient age (years)	-.12**	.06	-.03
Block 3 (Primary objective stressors-patient)			
Cognitive status (SPMSQ)	-.08*	.07	-.05
Activities of daily living (ADLI)	.09*	-.02	.07
Depression (CES-D)	.08*	-.01	.05
QOL (HQLI-14)	-.08*	.04	-.03
Symptom distress (MSAS)	.10**	-.03	.07
Pain	.08*	-.07	.02
Block 4 (Primary subjective stressors-caregiver)			
Physical health (PCS)	-.13***	.12**	-.13***
Emotional health (MCS)	-.59***	.19***	-.31***
Suicidal ideation	.21***	-.15***	.03
Block 5 (Mediators)			
Unmet spiritual needs (SNI)	.39***	-.33***	
Social support	-.32***		-.33***

Note. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$ (two-tailed, Pearson's product-moment correlation)

Multivariate Findings among Stress Process Domains

Parametric assumptions. Multivariate normality, linearity, and

homoscedasticity were examined via visual inspection of a linear regression plot. The

plot revealed a rectangular distribution of scores clustering in the center. This pattern satisfies parametric assumptions (Mertler & Vannatta, 2005). Multicollinearity was assessed by examining tolerance statistics and variance inflation factors (VIFs). In the final model (Model 5), tolerance statistics ranged from 0.29 to 0.94 and VIF values ranged from 1.07 to 3.41, suggesting that multicollinearity was not a problem (Mertler & Vannatta, 2005).

Research question #4. *What are the best predictors in identifying caregiver depression among hospice caregivers?* Multiple regression was used to identify sociodemographic and stress-related variables that predicted caregiver depression among hospice caregivers. A total of 16 predictor variables were included in the model. Variables were entered in sequential blocks to illustrate the unique contribution of each domain within the stress process model (Table 4.3).

As shown in Model 2 (Table 4.4), caregiver and patient demographic variables explained 9% of the variance in depressive symptoms, with income (e.g., lower), relationship to the patient (e.g., parent, spouse and adult child), and the patient's age (e.g., younger) significantly contributing to the model. The addition of the primary objective stressor in Model 3 increased the explanatory power of the model by 1%. With the exception of the cognitive functioning variable (i.e., SPMSQ), none of the other primary objective stressors contributed to the model (Table 4.4).

In model 4, the addition of the primary subjective stressors increased the explained variance in the model by 34%, ($R^2 = .45$, $R^2_{adj} = .44$, $F[12, 517] = 34.88$, $p < .001$). Examination of the standardized beta coefficients revealed that six variables significantly contributed to the model. Three of the variables, emotional health ($\beta = -.58$,

$t[517] = -16.7, p < .001$), physical health ($\beta = -.19, t[517] = -5.1, p < .001$) and relationship to the patient (e.g., spouse) ($\beta = .14, t[517] = 2.8, p < .01$) were primary predictors.

In the final model (Model 5), the addition of the mediating variables (i.e., social support and fulfillment of spiritual needs) further increased the explanatory power of the model by 4%, ($R^2 = .50, R^2_{\text{adj}} = .48, F[14, 515] = 36.15, p < .001$). Greater unmet spiritual needs ($\beta = .17, t[515] = 4.7, p < .001$) and less satisfaction with the amount of support received from others ($\beta = -.13, t[515] = -3.6, p < .001$) were significant predictors of depressive symptoms among hospice caregivers (Table 4.4).

Research question #5. *Do certain resources (i.e., social support and fulfillment of spiritual needs) mediate the relationship between caregiver depression and sociodemographic characteristics, primary objective stressors, and primary subjective stressors?* Several bivariate relationships emerged between sociodemographic characteristics, primary objective/subjective stressors, and mediating variables. In general, caregivers reported more unmet spiritual needs and less satisfaction with social support when they perceived their emotional and physical health as being strained, ($r = -.31$ and $r = .19, p < .001$; $r = -.13, p < .001$ and $r = .12, p < .01$, respectively) (Table 4.3). In addition, univariate analysis of variance revealed significant mean differences across relationship type to the patient for unmet spiritual needs, ($F[3, 713] = 2.95, p < .05$ and social support, $F[3, 697] = 3.67, p < .05$). Tukey's HSD post hoc test revealed that siblings reported the fewest unmet spiritual needs ($M = .71, SD = 1.7$) compared to spouses ($M = 1.4, SD = 2.2$). Regarding social support, although close, adult children ($M = 10.4, SD = 2.1$) reported being the least satisfied with the level of social support

received when compared to spouses ($M = 10.8$, $SD = 1.7$) and siblings ($M = 11.1$, $SD = 1.2$).

Table 4.4

Multivariate Hierarchical Regression among Stress Process Variables in Predicting Caregiver Depression

Stress Process Variables	Model 1	Model 2	Model 3	Model 4	Model 5
	<i>B</i>	β	β	β	β
Caregiver background and contextual factors					
Relationship (adult child)	.23 (3.7) ***	.28 (4.2) ***	.27 (4.1) ***	.11 (2.0) *	.08 (1.5)
Relationship (spouse)	.35 (5.6) ***	.35 (5.6) ***	.35 (5.6) ***	.14 (2.8) **	.13 (2.6) *
Relationship (parent)	.16 (3.5) ***	.13 (2.6) **	.12 (2.5) *	.08 (2.0)	.08 (2.2) *
Work status (unemployed, nor retired)	-.15 (-3.3) ***	-.10 (-1.9)	-.10 (-1.9)	-.05 (-1.1)	-.03 (-.70)
Income (low)	.19 (2.7) **	.19 (2.8) **	.19 (2.7) **	.07 (1.3)	.07 (1.3)
Patient background and contextual factors					
Patient age		-.11 (-2.2) *	-.12 (-2.4) *	-.06 (-1.5)	-.05 (-1.2)
Primary objective stressors (patient)					
Cognitive status (SPMSQ)			-.12 (-2.9) **	-.09 (-2.8) **	-.09 (-2.7) **
Subjective primary stressors (caregiver)					
Physical health (PCS)				-.19 (-5.1) ***	-.13 (-3.6) ***
Emotional health (MCS)				-.58 (-16.7) ***	-.51 (-14.3) ***
Suicidal ideation				.07 (2.1) *	.06 (1.7)
Mediators					
Unmet spiritual needs (SNI)					.17 (4.7) ***
Social support					-.13 (-3.6) ***
R^2	.09	.10	.12	.45	.50
R^2 adjusted	.08	.09	.10	.44	.48

Note. Standardized coefficients (β), with t -test values in parenthesis. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$ (two-tailed t -test).

Social support and unmet spiritual needs were also significantly related to caregiver depression. In general, the less satisfied a caregiver was with the level of support received from others, the greater the amount of depressive symptoms reported ($r = -.32, p < .001$). Similarly, as the number of unmet spiritual needs increased so did the number of depressive symptoms ($r = .39, p < .001$) (Table 4.3).

Mediating effects. A series of regression analyses were conducted to test the mediating effects of social support and unmet spiritual needs on the outcome variable, caregiver depression. Figure 4.1 shows the influence of social support on the direct relationship between the predictor variables and the outcome variable. When social support was added to the regression model, the direct effect of physical health ($\beta = -.09, t[693] = -2.5, p < .05$), suicidal ideation ($\beta = .16, t[693] = 4.42, p < .001$), and emotional health ($\beta = -.55, t[693] = -18.27, p < .001$) on caregiver depression was reduced. The direct effect of work status (i.e., unemployed) ($\beta = -.06, t[692] = -1.7, p = .09$) on caregiver depression when controlling for social support became nonsignificant. These findings satisfy Baron and Kenny's (1986) criteria for testing mediational effects. Results from the Aroian version of the Sobel test provided further evidence to support partial mediation between caregiver depression and the predictor variables, physical health ($z = -2.81, p < .01$), suicidal ideation ($z = 3.62, p < .001$), and emotional health ($z = -3.87, p < .001$), and full mediation between caregiver depression and work status ($z = -3.02, p < .01$).

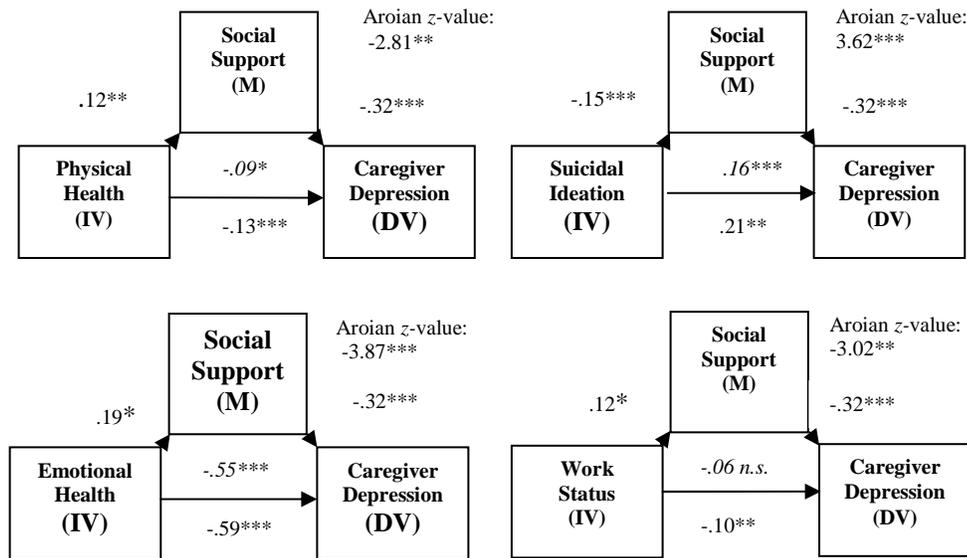


Figure 4.1. Complete and Partial Mediating Effects of Social Support on Caregiver Depression. Values indicate the standardized beta coefficients. Italicized numbers indicate the indirect pathway between the predictor variables and the dependent variable when controlling for social support. * $p < .05$, ** $p < .01$, *** $p < .001$, *n.s.* = not significant.

Figure 4.2 shows the indirect effect of the fulfillment of spiritual needs on the outcome variable. When this mediator was added to the regression model, the direct effect of the predictor variables, physical health ($\beta = -.08$, $t[708] = -2.4$, $p < .05$) and emotional health ($\beta = -.52$, $t[708] = -16.83$, $p < .001$) on caregiver depression decreased. The direct effect of work status (i.e., unemployed) ($\beta = -.07$, $t[707] = -1.94$, $p = .052$) on caregiver depression when controlling for unmet spiritual needs became nonsignificant. These findings satisfy Baron and Kenny's (1986) criteria for testing mediational effects. Results from Aroian's test of mediation indicated that the fulfillment of spiritual needs partially mediated the relationship between caregiver depression and the predictor variables, physical health ($z = -3.13$, $p < .01$) and emotional health ($z = -5.52$, $p < .001$),

and completely mediated the relationship between caregiver depression and work status ($z = -2.25, p < .05$).

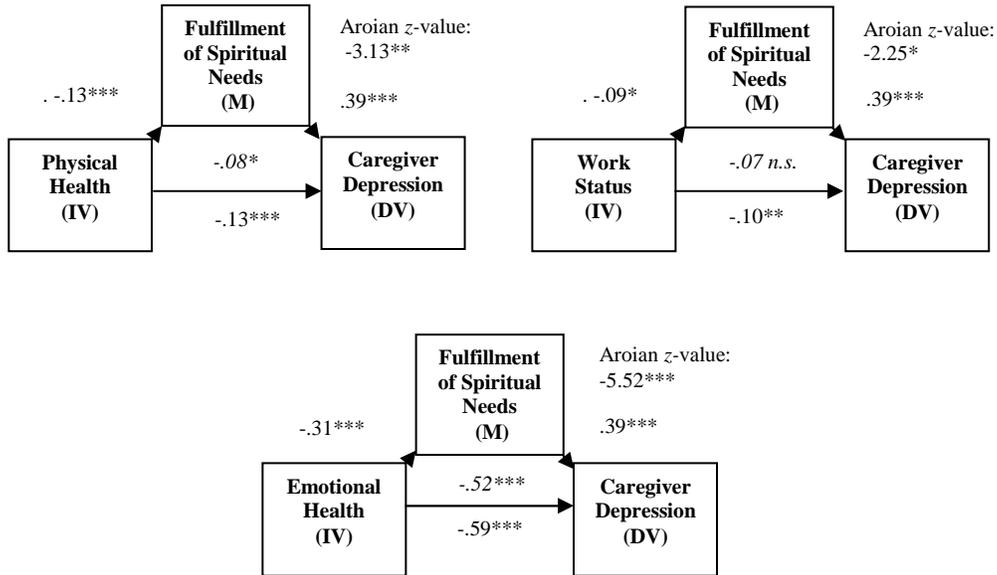


Figure 4.2. Complete and Partial Mediating Effects of the Fulfillment of Spiritual Needs on Caregiver Depression. Values indicate the standardized beta coefficients. Italicized numbers indicate the indirect pathway between the predictor variables and the dependent variable when controlling for the fulfillment of spiritual needs. $*p < .05$, $**p < .01$, $***p < .001$, *n.s.* = not significant.

CHAPTER 5: DISCUSSION

This chapter presents the discussion of study results. To date, stress and coping models are one of the most commonly used conceptual models to study the caregiving experience (Haley et al., 2003; Herbert & Schulz, 2006; Hudson, 2003). These models provide a comprehensive understanding of the “mix of circumstances, experiences, responses, and resources” that impact caregiver health and behavior (Pearlin et al., 1990, p. 14). By capturing the relationship between person and environment, the cognitive appraisal process, and the influence of mediating variables, these models have direct clinical utility in advancing assessment protocols and interventions. Utilizing Pearlin and colleagues’ stress process model of caregiving, this study investigated the caregiving experience from a subgroup of caregivers who are often understudied—hospice caregivers of terminally ill cancer patients. Results revealed both risk and protective factors associated with the development of depressive symptomatology. The best fit predictive model of caregiver depression included a mix of caregiver background and contextual factors, primary objective and subjective stressors, and mediating variables.

Sociodemographic Characteristics (Background and Contextual Factors)

Overall, the sample characteristics of this study were similar to other EOL caregiving studies (Doorenbos et al., 2007; Haley et al., 2003; Wilder et al., 2008). In

general, both patients and caregivers were mostly white and elderly. Almost all of the caregivers were female spouses. In addition, because a large proportion of this sample consisted of elderly couples, the majority was retired and reported incomes similar to national averages wherein a majority of older adults 65 years and older report incomes under \$35,000 (AOA, 2009) (Table 4.2)

One of the main limitations in this study is the lack of diversity in the sample. This may be explained in part by traditional trends in hospice care and the geographical location from which dyads were recruited. Historically, over the last several decades, hospice care has been utilized by mostly white, elderly patients (NHPCO, 2010). Minority populations are often underrepresented not only in hospice care but in EOL care research as well (McMillan & Rivera, 2009). African Americans and Hispanics, in particular, often face barriers that impede the referral and admission process into hospice, e.g., lack of knowledge or awareness of hospice services; language barriers; conflicts between hospice practice standards and cultural values/beliefs; and, mistrust of the healthcare system (Carrion, 2010; Colon & Lyke, 2003; Washington, Bickel-Swenson, & Stephens, 2008). Although every effort was made to recruit ethnically and racially diverse minorities, for the most part, dyads resided in predominately white communities. Because minority caregivers often provide greater levels of care, rely less on formal services, and experience economic, physical, and emotional strains (Dilworth-Anderson, Williams, & Gibson, 2002; Glajchen, 2004; Pinquart & Sorensen, 2005), future social work research should be directed at understanding and meeting the needs of these growing number of informal caregivers.

In addition, the sample mostly represented elderly females. The large sample of female caregivers may reflect caregiving norms and expectations. Moreover, advanced disease and chronic conditions often plague older adults. Although it is important to examine the caregiving experiences among older adults, future research also needs to pay attention to the changing trends occurring in our society. Advances in health and changes in the family system will continue to change the profile of future caregivers. For instance, elderly male spouses will be living longer and providing more care to their counterparts; adult children (e.g., the “boomers”) will serve as either sole caregivers or secondary helpers (Agree & Glaser, 2009). Yet, despite these limitations, the large sample size reflects the caregiving experience from one of the most vulnerable populations—elderly, female spouses.

Hypothesis #1. *It was hypothesized that female caregivers would experience greater levels of depression than males.* Although a large body of research suggests that female caregivers are more likely to experience depression than males (Yee & Schulz, 2000), this finding was unsupported (Appendix N, Table N3). In general, both males and females equally appeared to experience similar levels of depressive symptoms. This finding may partially reflect the time in which data were collected. Since baseline data were collected shortly after admission into hospice (i.e., 24-72 hours), regardless of gender, as a whole, caregivers may have had little time to think about their personal feelings and emotions. Instead, caregivers may have been preoccupied with trying to get services in place for patients. Moreover, caregivers may have also felt a surge of support from hospice staff which may have temporarily alleviated feelings of stress and/or

depression. Future studies are needed to examine whether gender differences emerge throughout the EOL care trajectory.

It was hypothesized that the relationship to the CR would be associated with caregiver depression. Specifically, adult daughters and wives would report more depressive symptoms than other caregivers. This hypothesis was partially supported. Although there was no significant difference in the number of depressive symptoms reported among adult children, spouses, or parents, differences did emerge between siblings/friends, parents and spouses. Siblings/friends reported the fewest depressive symptoms; while, parents and spouses reported the most symptoms. It is possible that such differences emerged because siblings/friends may have viewed their role as secondary to hospice services. Unlike parents and spouses who tend to provide around the clock care, siblings/friends may have been less involved in their loved ones' care. With fewer restrictions in normal activities and roles, these caregivers may have appraised their caregiving role as being less burdensome and stressful, thereby reducing the number of depressive symptoms reported. Future research is needed to explore the caregiving experience among siblings and other secondary helpers.

Conversely, since spouses usually assume caregiving responsibilities due to the inherent nature and role of marital relationships, it would be expected that these caregivers would face physical and emotional challenges. Whether this is due to physical strains associated with the caregiving role, emotional reactions resulting from concerns about the patient's QOL and/or suffering, or personal fears about losing a lifelong partner (Braun et al., 2007; Doorenbos et al., 2007; Gunnarsson & Ohlen, 2006; Jo et al., 2007; Lowenstein & Gilbar, 2000; Riley & Fenton, 2007; Sherman, 1998), the findings in this

study suggest that elderly spouses are at a heightened risk for depression. Compared to other caregivers, spouses may be more likely to witness and experience the day-to-day realities of living with and dying from cancer. They provide intimate personal care, assist with ADLs and IADLs, and share, whether spoken or not, emotions about the disease and dying process. Interestingly, in this sample, spousal caregivers were also more likely to provide assistance without the help of others, perhaps in a sense leaving them to feel alone and isolated, thus providing additional rationale as to why these caregivers reported more depressive symptoms. Having to endure the EOL caregiving role in isolation, without the emotional and/or physical support of others may be challenging especially for caregivers who often relied on their spouses to assist with day-to-day activities and/or difficult tasks.

In addition, being a parent to a terminally ill adult is just as challenging. In a qualitative study that examined parental experiences of terminally ill adult children, Dean and colleagues (2005) found that the need and desire to parent was often confronted with feeling of ineptness and helplessness. Parents were confronted with the stark reality that they could not make things better. Parents described their experiences as being devastating and unimaginable. Bearing witness to their children's impending death invoked feelings of heartache and despair. Losing a child may be perceived as unfair and untimely (Cacace & Williamson, 1996; Dean et al., 2005); and for some parents, the loss may be marked with ongoing feelings of grief (Arnold, Gemma, & Cushman, 2005).

It was hypothesized that younger, working females would experience higher levels of depression than younger and/or older, non-working females. Unexpectedly, there was no significant relationship between caregiver depression, work status (e.g., full or part-

time employment) and age. Although previous research has found that additional roles outside of the caregiving role may lead to emotional distress, especially among females (Gaugler et al., 2008; Given et al., 2004; Kim et al., 2006; Swanberg, 2006) this finding was not supported. A reasonable explanation may be attributed to the small sample size of younger adults who were working. Results did reveal, however, that unemployed caregivers (e.g., caregivers who reported being disabled or not retired) were more likely to report depressive symptoms (Table 4.3). Because disability status was negatively related to health, it may be assumed that the additive effect of caregiving poses additional strains to an already taxing situation. In addition, caregivers who were not retired (and also not working) may have reported more depressive symptoms simply because they felt isolated and disengaged from others. Research suggests that work and/or social roles may actually help to buffer the effects of caregiving as these roles appear to offer respite and social support (Cameron et al., 2002; Given et al., 2004, Swanberg, 2006).

It was hypothesized that caregivers with lower income and educational statuses would experience more depressive symptoms than their counterparts. Despite the limited research supporting the link between caregiver depression, education and income status (Gaugler et al., 2009; Goldstein et al., 2004; Matthews et al., 2003; Meyers & Gray, 2001), results revealed a significant relationship among these variables (Table 4.3). Because education and income are generally related to each other, in that lower levels of education are associated with lower incomes, it is reasonable to assert that less educated caregivers have fewer financial resources (Hudson, 2003; Weitzner et al., 1999). Living on a limited income in the midst of providing EOL care may pose additional threats to one's perceived ability to cope with the caregiving role (Li, 2005). This assertion may be

particularly relevant to older adults since these caregivers often live on fixed incomes. In addition, these caregivers may also be thinking about the future loss of their spouse's retirement income which may pose additional strains to the caregiving role. On the other hand, caregivers with higher incomes and educational statuses were less likely to be depressed. Perhaps, caregivers with more education may be better equipped to utilize appropriate coping strategies (e.g., using problem-focused coping strategies) and/or resources (e.g., access to support groups, educational materials) to deal with ongoing stressors (Andrykowski, Carpenter & Munn, 2003; Papastavrou, Charalambous & Tsangari, 2009). Further research is needed to examine the relationship among caregiver sociodemographic variables and coping strategies.

It was hypothesized that patient gender and age would be associated with caregiver depression. This hypothesis was also partially supported. Age was the only patient characteristic associated with caregiver depression (Table 4.3). It appeared that caregivers of younger patients had a much more difficult time caring for their loved ones. Perhaps, these caregivers felt as if their loved ones were being prematurely taken away from them. Having to be a parent or a spouse of a younger patient who is dying may be perceived as unfair, or as life course theorists would assert as an "off-time" life transition (Hutchinson, 2008). Unlike previous research (see Lim & Zebrack, 2004, for a review), it is unclear why patient gender was unrelated to caregiver depression. In this study, it appeared that regardless of the patient's gender, caregivers experienced similar levels of depression. Further research is needed to explore these relationships.

Primary Objective Stressors

Hypothesis #2. *It was hypothesized that higher levels of patient symptomatology would be negatively associated with caregiver depression. Specifically, caregivers of patients who had poorer cognitive and functional statuses, in addition to lower QOL scores would exhibit more depressive symptoms than caregivers of patients with better QOL and cognitive and functional statuses.* Overall, these hypotheses were supported. Findings revealed a significant relationship between patient symptomatology and caregiver depression (Table 4.3). Caregivers were more likely to report depressive symptoms when patients reported mild cognitive impairment, lower functional status, and poorer QOL. It should be noted, however, that the range of these correlations was extremely low, ranging from .08 to .09. Shared variances among these variables were under 1%.

Unlike previous research that has found moderate relationships among the aforementioned variables (Cameron et al., 2002; Pinquart & Sorensen, 2006; Redinbaugh et al., 2003; Rhee et al., 2008), the weak correlations in this study may be attributed to two issues. One, since the original study did not rely on proxy reports, but instead on self-report from patients, patients needed to be alert and oriented in order to participate (e.g., patients were excluded if they exhibited moderate to severe cognitive impairment, were 100% bedbound and required total care). Due to this criterion, both SPMSQ (i.e., cognitive status) and PPS (i.e., functional status) measures had restricted ranges. Consequently, this biased the study, skewing the sample to represent better functioning patients. Perhaps, this explains why QOL scores were negatively skewed (e.g., the mean QOL score was in the moderate range).

It was also hypothesized that caregivers of patients who exhibited pain and greater symptom distress and depression scores would experience more depressive symptoms than caregivers of patients with better emotional and physical health. These hypotheses were also supported. However, similar to the aforementioned stressors, there was also a weak relationship between these primary objective stressors and caregiver depression (Table 4.3). Patient depressive and symptom distress scores were positively skewed, reflecting fewer depressive symptoms and overall distress. Likewise, the shared variances among these variables ranged between 0.6 to 1%. As previously mentioned, the weak correlations may be attributed to patient selection (e.g., excluding severely debilitated patients).

Despite these findings, research provides substantial evidence to support that EOL care patients experience moderate levels of physical and/or emotional distress (Breitbart et al., 2000; Chochinov et al., 2009; Delgado-Guay, Parsons, Li, Palmer, & Bruera, 2009; Lidstone, Butters, Seed, Sinnott, Beynon, & Richards, 2003; Tranmer, Heyland, Dudgeon, Groll, Squires-Graham, & Coulson, 2003). These findings should not be disregarded. It is unclear why the majority of these patients, all of whom had a prognosis of six months or less, entered hospice care with minimal levels of physical and emotional distress. It is unrealistic to assume that hospice services attended to the physical and/or emotional needs of patients so quickly after admission (e.g., within 72 hours). Perhaps, a more plausible explanation may be attributed to the large sample of older patients. Research shows that older adults have a tendency to underreport symptoms (Given & Given, 2010). In addition, older patients may be more likely to perceive their health

problems in a fatalistic way; or in other words they may feel as if their health problems are inevitable.

In this study, further examination of the data provided some evidence to suggest that when compared to younger patients (i.e., < 65 years old), older patients (i.e., ≥ 65 years old) were indeed less likely to report emotional and physical distress. It is possible that older patients may minimize the severity of their symptoms as a way to protect their lifelong partners from emotional distress and/or suffering. McPherson and colleagues (2007) provide evidence to support this notion. Findings from her qualitative study revealed that patients concealed their needs (i.e., feelings and symptoms) not only as a way to protect caregivers from the physical, emotional, and social burdens associated with care, but also as a way to deflect self-perceived burden. However, in the original study, dyads were interviewed separately as a way to encourage and facilitate open and honest dialogue with both the patient and caregiver. Future research is needed to examine the relationship between self-perceived patient burden and caregiver depression.

Primary Subjective Stressors

Hypothesis #3. *It was hypothesized that poor overall health would be negatively associated with caregiver depression. Specifically, caregivers who perceived their emotional and/or physical health as being poor or strained would be more likely to report depressive symptoms than caregivers in better health.* Although the majority of caregivers in this sample reported being in good physical health, caregivers who perceived their physical health as being fair or poor were indeed more likely to report depressive symptoms. In addition, caregivers who perceived their emotional health as being strained also reported more depressive symptoms (Table 4.3). These caregivers

were not only more likely to experience physical and/or emotional exhaustion, but they were also limited in their ability to engage in normative roles and activities. These findings support existing research that asserts a negative relationship between health and psychological distress (Bainbridge et al., 2009; Dumont et al., 2006).

It is also worth noting that, as a whole, this study sample's mean physical and emotional health scores were below the average norms for the general population (Ware, 2000). A similar finding emerged among EOL caregivers in another study (Haley et al., 2001). Whether these findings reflect the fact that the majority of caregivers in this study were older and already experiencing health problems, or that the caregiving role depletes *adaptive energy*, which in turn restricts functionality to a degree, regardless of one's physical and/or emotional health, these caregivers still provided EOL care. Other studies have found that despite evidence of deteriorating health, older caregivers, in particular wives, will continue to provide substantial amounts of care to their loved ones (Brazil, Bedard, Willison, & Hode, 2003; Haley et al., 2001; Navaie-Waliser et al., 2002; Wolff et al., 2007). These findings are extremely alarming given that the future cohort of caregivers will represent older generations. Therefore, the focus of future social work practice and research should be directed toward developing, testing, and implementing practice interventions. Social workers will not only be able to expand the existing body of empirically-based social work interventions, but they will also be able to promote compassionate services and care that are culturally-sensitive and directed toward meeting the needs of at risk caregivers.

It was also hypothesized that there would be a direct positive relationship between suicidal ideation and depression. Caregivers who presented with suicidal

thoughts would report more depressive symptoms than caregivers without ideation. As expected, this hypothesis also was supported (Table 4.3). End of life caregivers, particularly older spouses, may be at a greater risk of experiencing suicidal thoughts and/or wishes because this phase in one's life can be marked with fears and/or uncertainties of living a life without the patient, feelings of helplessness and loss of control and/or emotional, physical, social, or spiritual suffering. These feelings and emotions are often characterized as precipitating factors that lead to anticipatory grief, and can eventually lead to more complicated forms of grief, wherein the bereaved individual has significant problems adjusting to the death of the patient (see Grassi, 2007, for review).

The fact that some caregivers in this study reported both depressive symptoms and suicidal ideation lends itself to future research, especially since depressive symptoms and/or thoughts about dying may intensify and persist after the death of the patient. Previous research has demonstrated a positive relationship between caregiver depression and suicidal ideation; however, other factors such as emotional loneliness and complicated grief have also been found to increase suicidality (i.e., suicidal ideation and behavior) and should be examined (Latham & Prigerson, 2004; Stroebe et al., 2005). Since bereaved individuals are at risk for experiencing psychological and physical morbidity, engaging in maladaptive behaviors (e.g., substance abuse), and have increased thoughts and/or wishes about death and dying (Grassi, 2007; Stroebe, Schut, Stroebe, 2007), the findings in this study have significant clinical implications that warrant further research and practice considerations.

Mediating Variables

Hypothesis #4. *It was hypothesized that caregivers with greater levels of social support and less unmet spiritual needs would experience less depressive symptoms than caregivers who had less support and more unmet needs.* Both social support and unmet spiritual needs were significantly related to caregiver depression, supporting the proposed hypothesis (Table 4.3). Caregivers who felt supported by family and/or friends and who were able to find meaning in their lives were less likely to report depressive symptoms. Among caregivers who were less satisfied with the level of social support received, these individuals not only reported more depressive symptoms, but they were also more likely to report unmet spiritual needs. These findings support other research that found a negative relationship between coping resources (i.e., social support and spirituality) and psychological well-being (Colgrove et al., 2007; Dumont et al., 2006; Fry, 2011; Gaugler et al., 2009; Haley et al., 2003; Tang, 2009; Waldrop et al., 2005).

A major goal in this study was to examine the role of two resources, social support and spirituality (as measured by the fulfillment of spiritual needs), and whether these variables mediated the relationships between stress-related variables and caregiver depression. Social support partially reduced the number of depressive symptoms among caregivers who had thoughts about death and dying and who also perceived their physical and emotional health as being strained. This resource completely mediated the relationship between work status and caregiver depression (Figure 4.1). Social support appeared to provide a sense of comfort and relief to caregivers who endured physical, emotional and/or social limitations. This finding highlights the need for social workers to

conduct ongoing assessments on the dynamics of the family support system, and to find ways to enhance social support of caregivers.

The fulfillment of spiritual needs, or in other words having very few or no unmet spiritual needs, also helped to partially reduce the number of depressive symptoms among caregivers who perceived their emotional and physical health as limited.

Interestingly, this protective factor also completely mediated the relationship between work status and caregiver depression (Figure 4.2). Finding meaning and purpose in life appeared to reduce depressive symptoms and in a sense enabled caregivers to turn to more adaptive ways to cope with care-related stressors. This finding also has important social work implications in that it highlights the need for social workers to assess spiritual needs, in addition to designing interventions that promote spiritual well-being.

The Spiritual Needs Inventory (SNI) measures a variety of needs (i.e., activities, thoughts, and experiences) that can provide meaning and purpose in one's life (Hermann, 2006). One of the subscales in this measure assesses the value of community (e.g., the importance of being around family, friends, children, etc). This particular dimension of spirituality appeared to be the most important to caregivers. If caregivers find value and meaning from being around loved ones and friends, and are unable to meet this need, feelings of isolation may result. If caregivers are dissatisfied with the level of support received, feelings of abandonment may emerge. Perhaps, a lack of connectedness with community and limited social support creates a sense of social isolation which in turn increases depressive symptomatology. This explanation provides some rationale as to why caregivers who lacked physical and emotional support reported more depressive symptoms and unmet spiritual needs. Moreover, it is also possible that depressed

caregivers were not able to perceive or benefit from social support available to them. Further research is needed to explore other possible mechanisms or pathways in predicting caregiver depression.

Stress Outcomes

Hypothesis #5. *It was hypothesized that the best fit predictive model would include an array of variables, with primary subjective stressors contributing the most unique variance to the model.* Overall, the final model accounted for 48% of the variance in caregiver depression, with relationship to the patient, physical health, emotional health, patient cognitive status, fulfillment of spiritual needs, and social support significantly contributing to the model (Table 4.4). In sum, caregivers were more likely to experience depressive symptomatology if they cared for a patient with mild cognitive impairment; identified themselves as either a spouse or parent; perceived their emotional and/or physical health as being poor or strained; and, reported more unmet spiritual needs and less satisfaction with the amount of support received from others. Of all of the variables in the model, primary subjective stressors (i.e., emotional and physical health) contributed the most unique variance, supporting the proposed hypothesis and existing research that asserts that subjective stressors appear to be stronger predictors of caregiver well-being (Gaugler et al., 2009; Haley et al., 2003; Kim et al., 2007; Matthews et al., 2004).

Findings highlight several subgroups of caregivers who were at a greater risk of experiencing depressive symptoms. Spouses and parents appeared to be a particularly vulnerable group of caregivers. Because these caregivers often live with patients, they bear witness to the ongoing trials and tribulations of living with and dying from cancer.

Caregivers who cared for patients with cognitive impairments were also at a heightened risk. Caring for a loved one with memory impairments may be especially challenging because caregivers may perceive this symptom as another sign of decline, and to some extent, separation from the patient. Moreover, one of the most vulnerable groups of caregivers identified were those who perceived their own physical and/or emotional health as being strained. Even in the midst of one's own suffering, these caregivers continued to provide one of the most challenging forms of care. Limitations in health may pose significant impairments to the caregiver's ability to provide adequate care to the patient and oneself (Dumont et al., 2006).

In addition, results provided further evidence to support the buffering effects of two protective factors, social support and the fulfillment of spiritual needs. Both of these coping resources helped to lessen the effects of caregiver depression even among the most vulnerable caregivers. In this study, both variables appeared to empower or instill strength. It may be assumed that EOL caregivers who are able to find meaning in life through spiritual activities and who also feel supported by others may be in a better position to find meaning within the caregiving role and/or view the caregiving experience in a positive way. Further research is needed to examine the relationship between coping resources and caregiver outcomes.

Limitations and Strengths

There are several limitations in this study. First and foremost, this research confines itself to the study of the EOL caregiving experience from two hospices in southwest Florida that mostly served older, Caucasian patients and caregivers. The sample therefore does not represent dyads from younger cohorts or ethnic/racial minority

groups. This deserves special attention considering that the number of ethnically and racially diverse groups is on the rise. Future research is needed to explore the EOL caregiving experience among minority and younger caregiver populations. Second, it is likely that selection bias skewed the sample to reflect better functioning patients. Because research assistants were involved in the screening and recruitment process of patient-caregiver dyads, they may have served as gatekeepers. Patients who appeared to have more symptoms or problems at admission may not have been screened as possible participants, thereby restricting the sample to patients who had better prognoses. Therefore, due to lack of diversity and possible bias, generalizability is limited.

Third, as with the use of any secondary data source, the dataset was restricted to variables and measures from the original study. As a result, some of the selected measures were limited in scope. For example, instead of using the SNI to measure unmet spiritual needs, other measures such as the 12-item Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-Sp) scale (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002) and the 20-item Spiritual Well-Being (SWB) scale (Ellison, 1983) could have been used to tap into dimensions of spiritual well-being or spiritual QOL. In addition, although the Short Form Health Survey-12 (SF-12) is a valid and reliable instrument that assesses emotional and physical health, it does not fully capture perceptions of overall caregiver burden and role overload. The Caregiver Stress Scale (Pearlin et al., 1990), a commonly utilized measure in EOL caregiving studies (Gaugler et al., 2008; Kim et al., 2007; Matthews et al., 2004), is an alternative measure that could have been used to measure negative perceptions of the caregiving role (e.g., emotional strain, overload, and loss of intimate exchange). Moreover, this study did not examine

how secondary stressors impact the caregiving experience. Further research will be needed to examine the impact of subjective stressors (e.g., burden) and the role of spirituality on the emotional well-being of hospice caregivers.

Because measures were self-report, social desirability may have resulted in the underreporting of certain symptoms or feelings. Future research should utilize a mixed methods approach to capture a more in-depth, or “thick description” of the EOL caregiving experience. Finally, due to the cross-sectional design, causal inferences cannot be made. It is unknown whether caregivers suffered from depression prior to their loved one’s admission into hospice. It is possible that these caregivers were already feeling isolated and disinterested in spiritual activities. Future research is needed to investigate the caregiving role at different points in time throughout the hospice experience.

Despite the aforementioned limitations, there were several strengths of the study that should be highlighted. First, it should be noted that the original study was one of the largest EOL care studies to date (McMillan, Small, & Haley, 2010). Therefore, it was possible to examine the relationships among multiple study variables within the stress process model of caregiving. This allowed for a more holistic way to examine various risk and protective factors associated with caregiver depression, thus providing a greater understanding of caregivers who are at greater risk. This provides direct implications for social work practice and research. Second, findings from this study further validate the utility of the stress process model of caregiving with EOL care populations. Third, it is noteworthy that despite challenges in conducting hospice research, in this study, many families wanted to participate. For the most part, dyads felt the need to “give back” to

hospice. Others felt that their contribution to research could help to make a difference in the future care of hospice families. This altruistic trait is one important thing that makes caregivers so valuable.

Implications for Social Work Research and Practice

Within the context of hospice care, research provides unnerving evidence to suggest that there is a lack of meaningful communication between caregivers and hospice personnel (Demiris, Oliver, & Wittenberg-Lyles, 2009). Because the philosophy of hospice and palliative care highlights the need to recognize the patient and caregiver as the *unit of care*, these findings are quite alarming. If hospice professionals fail to include caregivers within the context of care, caregivers may feel devalued and alienated. The end result could lead to a stressful care environment for both patient and caregiver. Hospice social workers can play a pivotal role in improving the delivery of hospice care by helping to facilitate better communication between caregivers and the hospice team, and by also improving the development of hospice assessments and interventions to meet the needs of the family system.

The stress process model of caregiving helps to bridge the gap between theory and social work practice. This well-tested theoretical model can serve as a guide to help social work practitioners develop comprehensive assessment measures that adequately assess sources of stress. Such measures should capture background characteristics of the patient and caregiver, as well as risk and protective factors. For example, background characteristics describe the personal attributes and/or situational factors that caregivers bring to the caregiving situation. By examining these factors, social workers are better equipped to identify and understand how these characteristics influence the way

caregivers appraise the caregiving situation. It is also essential to assess risk factors, both primary objective and subjective stressors, and how these stressors invoke negative appraisals of the caregiving role. Assessment measures should also take into account secondary stressors. This would enable social workers to assess the caregivers' "environment" and whether or not the caregiving role interferes with work, family and/or social roles. By conducting a thorough examination of these stressors, social workers are better able to identify needs and develop treatment goals and plans that may help to alleviate distress.

By conducting thorough assessments of the caregiving situation and by engaging in ongoing efforts to communicate with caregivers, social workers can utilize the stress process model to also develop interventions that promote sources of strength, an important social work value and principle. For example, if family support is a main source of strength, social workers could design therapeutic interventions that include family feedback and support. If spirituality is an important internal resource, social workers could collaboratively work with chaplains to develop care plans to meet spiritual needs. Such interventions may boost confidence and self-determination which in turn may help to facilitate positive EOL caregiving experiences. In addition, social workers can advance practice and research by evaluating the effectiveness of such interventions. This in turn will help to advance scientific knowledge by adding to the body of evidence-based social work practices.

Conclusion

EOL caregivers play an important role in meeting the needs of their loved ones. They devote countless hours providing physical, emotional, social, and spiritual care. As

members of the care team, they work hand-in hand with hospice professionals to try to make the final months, weeks, or days of a loved one's life free from pain and distress. While it is important to care for the dying patient, the needs of caregivers must also be recognized. Aligned with the same practicing principles and goals as in hospice care, social workers can play an active role in delivering comprehensive services that strive to preserve and promote the dignity and worth of both patients and their caregivers.

In order to deliver services to meet the needs of caregivers, it is important to first understand the complexities of the caregiving experience. Social workers, in particular, are in ideal roles to meet the ever changing demands and needs of complex family systems. The stress process model of caregiving provides a holistic way of examining the relationship between the patient, caregiver, and the caregiving environment (i.e., person-in-environment). This model offers a comprehensive way of examining the relationship between risk and protective factors. Therefore, by utilizing this model in practice, social workers are better able to develop holistic assessment measures and interventions that target specific sources of stress.

As social workers continue to play a critical role in EOL care, we need to push forward in advancing the goals outlined in the National Agenda for Social Work Research in Palliative and End of Life Care (see Kramer et al., 2005 for review). With this in mind, our next steps should be directed at developing, implementing, and testing interventions that contribute to the existing body of evidence-based practices. In addition, with the increasing number of diverse caregivers in the horizon, social workers will need to be cognizant that services and interventions are ethically and culturally appropriate and in alignment with the needs of the family unit. Our mission to deliver

compassionate care aimed at promoting resiliency, enhancing QOL, and fostering the dignity and worth of both the patient and caregiver will become increasingly more important in years to come.

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APPENDICES

**Appendix A:
Demographic Data Form Patient**

1. *Today's Date:* _____ 2. *Age:* _____

3. *Gender:* _____ male _____ female

4. *Relationship to Caregiver:* (circle number)

- | | |
|-------------|----------------------|
| 1. wife | 6. son |
| 2. husband | 7. brother |
| 3. mother | 8. sister |
| 4. father | 9. significant other |
| 5. daughter | 10. other |

5. *Marital Status* (circle one number)

- | | |
|----------------------|-------------|
| 1. never married | 4. divorced |
| 2. currently married | 5. widowed |
| 3. separated | |

6. *Ethnic background* (circle one number)

- | | |
|----------------------------------|----------------------------------|
| 1. Caucasian | 6. Mixed (please specify): _____ |
| 2. African American | 7. Other (please specify): _____ |
| 3. Hispanic | |
| 4. Asian/Pacific Islander | |
| 5. Eskimo/Native American Indian | |

7. *Number of years of school completed:* _____

8. *Cancer diagnosis:* _____ 9. *Months since diagnosis:* _____

10. *Current living arrangement* (circle one number)

1. live alone
2. live with spouse/partner
3. live with spouse/partner and children
4. live with children (no spouse/partner)
5. live with roommate who is not spouse/partner
6. live with parents
7. Other: specify _____

11. *Which category best describes your current or most recent job?* (circle one number)

1. Professional (e.g. teacher/professor, nurse, lawyer, physician, engineer)
2. Manager/administrator (e.g., sales managers)
3. Clerical (e.g. secretary, clerk, mail carrier)
4. Sales (e.g. sales person, agent, broker)
5. Service (e.g. police, cook, waitress, hairdresser)
6. Skilled crafts, repairer (e.g. carpenter, electrician)
7. Equipment or vehicle operator (e.g. truck drivers)
8. Laborer (e.g. maintenance, factory workers)
9. Farmer (e.g. owners, managers, operators, tenants)
10. Member of military

11. Homemaker (with no job outside of the home)

12. Other (please describe) _____

12. Religious affiliation (if any): _____

13. Home is in: Urban area _____

Suburban area _____

Rural area _____

**Appendix B:
Demographic Data Form Caregiver**

1. *Today's Date:* _____ 2. *Age:* _____

3. *Gender:* _____ male _____ female

4. *Relationship to Patient:* (circle number)

- 1. wife 6. son
- 2. husband 7. brother
- 3. mother 8. sister
- 4. father 9. significant other
- 5. daughter 10. Other _____

5. *Marital Status:* (circle one number)

- 1. never married 4. divorced
- 2. currently married 5. widowed
- 3. separated

6. *Ethnic background:* (circle one number)

- 1. Caucasian 6. Mixed (please specify): _____
- 2. African American 7. Other (please specify): _____
- 3. Hispanic
- 4. Asian/Pacific Islander
- 5. Eskimo/Native American Indian

7. *Number of years of school completed:* _____

8. *Are there other caregivers who routinely help you to provide care?* ___yes ___no

If yes, how many? _____

9. *Current living arrangement:* (circle one number)

- 1. live alone
- 2. live with spouse/partner
- 3. live with spouse/partner and children
- 4. live with children (no spouse/partner)
- 5. live with roommate who is not spouse/partner
- 6. live with parents
- 7. Other: specify _____

10. *Current employment situation:*

- A. Working 1. Full time 2. Part time
- B. On leave 3. With pay 4. Without pay
- C. Not employed 5. Disabled 6. Seeking work 7. Retired 8. Supported by other (e.g., spouse, parents)
- D. Student 9. Full time 10. Part time

11. Which category best describes your current or most recent job (circle one number)

1. Professional (e.g. teacher/professor, nurse, lawyer, physician, engineer)
2. Manager/administrator (e.g., sales managers)
3. Clerical (e.g. secretary, clerk, mail carrier)
4. Sales (e.g. sales person, agent, broker)
5. Service (e.g. police, cook, waitress, hairdresser)
6. Skilled crafts, repairer (e.g. carpenter, electrician)
7. Equipment or vehicle operator (e.g. truck drivers)
8. Laborer (e.g. maintenance, factory workers)
9. Farmer (e.g. owners, managers, operators, tenants)
10. Member of military
11. Homemaker (with no job outside of the home)
12. Other (please describe) _____

12. Approximate Annual Household Income:

- less than \$10,000
- \$10,000 - \$19,999
- \$20,000 - \$29,999
- \$30,000 - \$49,999
- \$50,000 - \$69,999
- \$70,000 - \$99,999
- over \$100,000

13. Religious affiliation (if any): _____

Appendix C:
Short, Portable Mental Status Questionnaire (SPMSQ)

Instructions: Ask questions 1-10 in this list and record all answers. Ask question 4A only if subject does not have a telephone. Record total number of errors based on ten questions.

1.	+	-	1. What is the date today? month, day, and year?
2.			2. What day of the week is it?
3.			3. What is the name of this place?
4.			4. What is your telephone number?
4A.			4A. What is your street address? (Ask only if patient does not have a telephone)
5.			5. How old are you?
6.			6. When were you born?
7.			7. Who is the president of the U. S. now?
8.			8. Who was president just before him?
9.			9. What was your mother's maiden name?
10.			10. Subtract 3 from 20 and keep subtracting 3 from each new number you get, all the way down.

SCORING:

0-2 errors: normal mental functioning

3-4 errors: mild cognitive impairment

5-7 errors: moderate cognitive impairment

8 or more errors: severe cognitive impairment

Source: Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of American Geriatrics Society*. 23, 433-441.

**Appendix D:
Activities of Daily Living (ADL) Index**

BATHING: Sponge bath, tub bath, or shower.		
<input type="checkbox"/> Receives no assistance (gets into and out of tub by self if tub is the usual means of bathing)	<input type="checkbox"/> Receives assistance in bathing only one part of the body (such as the back of a leg).	<input type="radio"/> Receives assistance in bathing more than one part of the body (or not bathed).
DRESSING: Get clothes from closets and drawers, including underclothes and outer garments, and uses fasteners, including suspenders if worn.		
<input type="checkbox"/> Gets clothes and gets completely dressed without assistance	<input type="checkbox"/> Gets clothes and gets dressed without assistance except for tying shoes.	<input type="radio"/> Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed.
TOILETING: Goes to the room termed "toilet" for bowel movement/urination, cleans self afterward, and arrange clothes.		
<input type="checkbox"/> Goes to toilet room. Clean self, and arrange clothes without assistance. (May use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying it in morning.)	<input type="radio"/> Receives assistance in going to toilet room or in cleaning self or arranging clothes after elimination or in use of night bedpan or commode.	<input type="radio"/> Doesn't go to toilet room for the elimination process.
TRANSFER		
<input type="checkbox"/> Moves into and out of bed as well as into and out of chair without assistance. (May use object such as cane or walker for support.)	<input type="radio"/> Moves into or out of bed or chair with assistance	<input type="radio"/> Doesn't get out of bed.
CONTINENCE		
<input type="checkbox"/> Controls urination and bowel movement completely by self.	<input type="radio"/> Has occasional accidents	<input type="radio"/> Supervision helps keep control of urination or bowel movement, or catheter is used, or is incontinent.
FEEDING		
<input type="checkbox"/> Feeds self without assistance .	<input type="checkbox"/> Feeds self except for assistance in cutting meat or buttering bread.	<input type="radio"/> Receives assistance in feeding or is fed partly or completing through tubes or by IV fluids.

Adapted with permission from Katz, S., Ford, A., Maskowitz, R, et al. (1963). The index of ADL—a standardized measure of biological and psychosocial function. *JAMA*, 185, 914-919. Copyright 1963, American Medical Association.

**Appendix E:
Palliative Performance Scale (PPS)**

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
100	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90	Full	Normal Activity Some Evidence of Disease	Full	Normal	Full
80	Full	Normal Activity with Effort Some Evidence of Disease	Full	Normal or Reduced	Full
70	Reduced	Unable Normal Job / Work Some Evidence of Disease	Full	Normal or Reduced	Full
60	Reduced	Unable Hobby / House Work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
50	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance Necessary	Normal or Reduced	Full or Confusion
40	Mainly in Bed	As Above	Mainly Assistance	Normal or Reduced	Full or Drowsy or Confusion
30	Totally Bed Bound	As Above	Total Care	Reduced	Full or Drowsy or Confusion
20	As Above	As Above	Total Care	Minimal Sips	Full or Drowsy or Confusion
10	As Above	As Above	Total Care	Mouth Care Only	Drowsy or Coma
0	Death	-	-	-	-

Adapted with permission from Anderson, F., Downing, G. M., & Hill, J. (1996). Palliative Performance Scale (PPS): a new tool. *Journal of Palliative Care* 12(1), 5-11.

Appendix F:
1-Item Pain Question-Patient

1. Do you have pain (yes) or (no)

**Appendix G:
Memorial Symptom Assessment Scale (MSAS)**

Directions: There are 25 symptoms listed below. Read each one carefully. If you have this symptom, check the “do have” box. Then circle the number that indicates **how severe it is** and **how much this symptom distresses or bothers you**.

	Symptom	Do have	How severe is this symptom?					How much does it distress or bother you?				
			Not at all	A little bit	Some-what severe	Severe	Very Severe	Not at all	A little bit	Somewhat	Quite a bit	Very much
1	Difficulty concentrating		0	1	2	3	4	0	1	2	3	4
2	Pain		0	1	2	3	4	0	1	2	3	4
3	Lack of energy		0	1	2	3	4	0	1	2	3	4
4	Cough		0	1	2	3	4	0	1	2	3	4
5	Feeling nervous		0	1	2	3	4	0	1	2	3	4
6	Dry mouth		0	1	2	3	4	0	1	2	3	4
7	Nausea		0	1	2	3	4	0	1	2	3	4
8	Vomiting		0	1	2	3	4	0	1	2	3	4
9	Feeling drowsy		0	1	2	3	4	0	1	2	3	4
10	Numbness/tingling in hands/feet		0	1	2	3	4	0	1	2	3	4
11	Difficulty sleeping		0	1	2	3	4	0	1	2	3	4
12	Feeling bloated		0	1	2	3	4	0	1	2	3	4
13	Problems with urination		0	1	2	3	4	0	1	2	3	4
14	Shortness of breath		0	1	2	3	4	0	1	2	3	4
15	Diarrhea		0	1	2	3	4	0	1	2	3	4
16	Feeling sad		0	1	2	3	4	0	1	2	3	4
17	Sweats		0	1	2	3	4	0	1	2	3	4
18	Worrying		0	1	2	3	4	0	1	2	3	4
19	Problems with sexual interest or activity		0	1	2	3	4	0	1	2	3	4
20	Itching		0	1	2	3	4	0	1	2	3	4
21	Lack of appetite		0	1	2	3	4	0	1	2	3	4
22	Dizziness		0	1	2	3	4	0	1	2	3	4
23	Difficulty swallowing		0	1	2	3	4	0	1	2	3	4
24	Feeling irritable		0	1	2	3	4	0	1	2	3	4
25	Constipation		0	1	2	3	4	0	1	2	3	4

**Appendix H:
Hospice Quality of Life Index-14**

The questions listed below ask about how you are feeling at the moment and how your illness has affected you. Please **circle the number on the line** under each of the questions, that best shows what is happening to you at the present time.

1) How well do you sleep?

not at all 0__1__2__3__4__5__6__7__8__9__10 very well

2) How breathless do you feel?

extremely 0__1__2__3__4__5__6__7__8__9__10 not at all

3) How well do you eat?

poorly 0__1__2__3__4__5__6__7__8__9__10 very well

4) How constipated are you?

extremely 0__1__2__3__4__5__6__7__8__9__10 not at all

5) How sad do you feel?

very sad 0__1__2__3__4__5__6__7__8__9__10 not at all

6) How worried do you feel about your family and friends?

very worried 0__1__2__3__4__5__6__7__8__9__10 not at all

7) How satisfied do you feel with your ability to concentrate on things?

very dissatisfied 0__1__2__3__4__5__6__7__8__9__10 very
satisfied

8) How much enjoyable activity do you have?

None 0__1__2__3__4__5__6__7__8__9__10 a great deal

9) How satisfied are you with your level of independence?

very dissatisfied 0__1__2__3__4__5__6__7__8__9__10 very
satisfied

10) How satisfied are you with the physical care that you are receiving?

very dissatisfied 0__1__2__3__4__5__6__7__8__9__10 very
satisfied

11) How satisfied are you with the emotional support you get from your health care
team?

very dissatisfied 0__1__2__3__4__5__6__7__8__9__10 very
satisfied

12) How satisfied are you with your relationship with God (however you define that
relationship)?

very dissatisfied 0__1__2__3__4__5__6__7__8__9__10 very
satisfied

13) Do your surroundings help improve your sense of well-being?

Not at all 0__1__2__3__4__5__6__7__8__9__10 very much

14) If you experience pain, how completely is it relieved?

No relief 0__1__2__3__4__5__6__7__8__9__10 complete relief

How bad is your pain when it is at its worst?

No pain 0__1__2__3__4__5__6__7__8__9__10 worst possible

**Appendix I:
SF-12 Health Survey**

Instructions: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

1. In general, would you say your health is:

- Excellent Very good Good Fair Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?

- Yes, limited a lot Yes, limited a little No, not limited at all

3. Climbing several flights of stairs

- Yes, limited a lot Yes, limited a little No, not limited at all

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?

4. Accomplished less than you like

- Yes No

5. Were limited in the kind of work or other activities

- Yes No

During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

6. Accomplished less than you like

- Yes No

7. Didn't do work or other activities as carefully as usual

- Yes No

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all A little bit Moderately Quite a bit Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

9. Have you felt calm and peaceful?

All the time Most of the time A good bit of the time Some of the time
 A little of the time None of the time

10. Did you have a lot of energy?

All the time Most of the time A good bit of the time Some of the time
 A little of the time None of the time

11. Have you felt downhearted and blue?

All the time Most of the time A good bit of the time Some of the time
 A little of the time None of the time

12. During the past 4 weeks, how much of the time has your physical or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

All the time Most of the time Some of the time A little of the time
 None of the time

Source: Adapted from Ware, J. E., Kosinski, M., Keller, S. D. (1996). A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34(3), 220-233.

**Appendix J:
SCID-Suicide Assessment**

Ask: “Over the past week were things ever so bad that you were thinking a lot about death or that you would be better off not living?” _____

If yes:

- A) Have you thought about actually harming yourself?**
- B) If so, do you have a plan/intention to harm yourself?**

Code:

0 = no information

1 = not at all

2 = slight, e.g., occasional thoughts “I would be better off dead”

3 = mild, e.g., frequent thoughts, no plan

4 = moderate, e.g., often thinks of suicide or has specific plan

5 = severe, e.g., often thinks of suicide; has mentally rehearsed a plan or verbal gesture

6 = extreme, e.g., has prepared for a serious suicide attempt

7 = very extreme, e.g., suicidal attempt with definite attempt to die

**Appendix K:
Received Support and Satisfaction Subscale**

Directions: Please circle the number below the answer that most closely matches your own. There are no right or wrong answers.

	Not at all	Little	Moderately	Very
1. Overall how satisfied in the last month have you been with the help you received with transportation, housework and yard work, and shopping	1	2	3	4
2. Overall, how satisfied in the last month have you been with support during difficult times, comforting from others, how others have listened, and interest and concern from others?	1	2	3	4
3. Overall, how satisfied in the last month have you been with the suggestions, clarifications, and sharing of similar experiences from others?	1	2	3	4

Source: Adapted from Krause, M., & Borawski-Clark, E. (1995). Social class differences in social support among older adults. *The Gerontologist*, 35(4), 498-508.

Appendix L: Spiritual Needs Inventory

Directions: This questionnaire contains 17 phrases that describe needs (activities, thoughts, or experiences) that some people have said they have during times of stress. For some people these needs relate to the spiritual part of them. They define spiritual as that part of them that tries to find meaning and purpose in life. They believe a spiritual need is something they need or want in order to live their lives fully. Please mark the items that you consider to be your spiritual needs, and which of these are currently not met.

Read the need in column A and then the questions in columns B and C before going on to the next need.

Column A In order to live my life fully, I need to:	Column B Please rate the items in the column below. For every item in the column that you answer 2 or higher, please answer yes or no in Column C					Column C Is this need being met in your life right now?	
	Never	Rarely	Sometimes	Frequently	Always	Yes	No
1. Sing/listen to inspirational music	1	2	3	4	5		
2. Laugh	1	2	3	4	5		
3. Read a religious text (for example, Bible, Koran, Old Testament)	1	2	3	4	5		
4. Be with family	1	2	3	4	5		
5. Be with friends	1	2	3	4	5		
6. Talk with someone about spiritual issues	1	2	3	4	5		
7. Have information about family and friends	1	2	3	4	5		
8. Read inspirational materials	1	2	3	4	5		
9. Use inspirational materials (for example, repeating or living by phrases or poems)	1	2	3	4	5		
10. Be around children (own or others' children)	1	2	3	4	5		
11. Be with people who share my spiritual beliefs	1	2	3	4	5		
12. Pray	1	2	3	4	5		
13. Go to religious services	1	2	3	4	5		
14. Think happy thoughts	1	2	3	4	5		
15. Talk about day to day things	1	2	3	4	5		
16. See smiles of others	1	2	3	4	5		
17. Use phrases from religious texts (for example: using phrases to guide you each day such as "greater is He that is in me, than He that is in the world")	1	2	3	4	5		

Other spiritual needs identified by the caregiver: _____

Source: Adapted from Hermann, C. P. (2006). Development and testing of the Spiritual Needs Inventory for patients near the end of life. *Oncology Nursing Forum*, 33(4), 737-744.

Appendix M:
Center for Epidemiological Studies Depression Scale (CES-D)

Did you experience the following much of the time during the past week?

YES	NO	
_____	_____	I felt depressed
_____	_____	I felt that everything I did was an effort
_____	_____	My sleep was restless
_____	_____	I was happy
_____	_____	I felt lonely
_____	_____	People were unfriendly
_____	_____	I enjoyed life
_____	_____	I felt sad
_____	_____	I felt that people disliked me
_____	_____	I could not get going

Source: Adapted from Kohout, F. J., Berkman, L. F., Evans, D. A., Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Health and Aging, 5, 179-193*

Appendix N: Preliminary Analysis of Data

Mapping of the Variables

Preliminary analysis of the baseline data was conducted to determine if the variables in the dataset mapped onto at least four of the domains of the stress process model. Drawing from the literature review presented in Chapter 2, in addition to obtaining expert consensus from EOL care researchers, variables from the original study were selected to map onto the background and contextual domain, primary stressor domains, mediating domain, and the stress outcome domain of the model (Table 1).

For the background and contextual domain, there were 10 caregiving variables and 2 patient variables identified. Twelve variables were identified for the primary objective and subjective stressor domains. None were identified for the secondary stressor domain. For the mediating domain, two variables were identified, and one variable was identified for the stress outcome domain. Next, the validity and reliability of the measures were examined along with the quality of the data (e.g., number of missing cases, variability in the data).

Table N1: Mapping of the Stress Process Variables

Domain	Background and Contextual		Primary Objective Stressor (Patient)	Primary Subjective Stressor (Caregiver)	Mediator (Care-giver)	Outcome (Caregiver)
	Patient	Caregiver				
Variable	Age	Age	Cancer History	Suicidal ideation (1-item)	Fulfillment of spiritual needs (SNI)	Depression (CES-D)
	Gender	Gender	Cognitive Status (SPMSQ)	Perceived Health status (physical and emotional) (SF-12)	Social support (3-item)	
		#other cgs	Pain (1-item)			
		Relationship to patient	Functional Status (ADLI & PPS)			
		Marital status	Depression (CES-D)			
		Ethnicity	Suicidal ideation (1-item)			
		Education	QOL (HQOL14)			
		Working status	Symptom distress (MSAS)			
		Income				
		Religion				

Validity and Reliability of the Measures

It is critical for researchers to select reliable and valid measures in order to minimize measurement error and to avoid jeopardizing the credibility and utility of research findings (Rubin & Babbie, 2011). The principal investigator (PI) of the original study selected measures that (a) have been widely used in clinical and/or research settings with various populations, (b) have good psychometric properties, and, (c) have been reviewed by experts for use with EOL care populations (e.g., considering instrument length and burden issues). Based on the review of the literature and psychometric findings, the measures for this study have been found to have acceptable to excellent

psychometric properties (Table 2). In addition, because the PI utilized a similar conceptual framework (e.g., Emanuel and Emanuel's model (1998) for a peaceful death) to design the original study, variables are being conceptualized and operationalized in a comparable way. Although measurement issues may be viewed as a limitation in secondary studies (Kiecolt & Nathan, 1985), this does not appear to be a major concern in the proposed study. The selected instruments are not only reliable and valid, but they also are designed to measure key concepts within the stress process model.

Quality of the Data

Missing data. Accuracy and completeness of data is an important factor to consider when assessing the quality of secondary data (Garmon-Bibb, 2007). Missing data can lead to serious limitations including a smaller sample size, limited statistical power, and biased results that can impact the validity and reliability of a study's findings (Grace-Martin, 2001). In order to examine the quality of the data, descriptive statistics (e.g., frequencies, measures of central tendency, measures of dispersion, and distribution measures) were used to determine the degree of missing data for each measure.

In general, the majority of patients and caregivers completed all of the baseline measures. The amount of missing data for each measure was sparse, ranging from 0 to 6% (Table 2). Of the 13 measures from the original study that will be used in this secondary analysis, the majority ($n = 7$) of the measures had less than 1% of missing data. The limited amount of missing data may be reflected in the level of data control in the original study (i.e., extensive training of the RAs, audits, cross-checking of measurements for errors and missing data).

Variability of the data. In addition to evaluating the amount of missing data, the degree of variability in each measure was also examined. It is important to examine the variance within measures in order to determine if there is a restricted range in the data. This is of particular importance when examining the relationship or correlation between variables. Measures that do not represent a full range of possible values may lead to erroneous conclusions when making assumptions about the relationship between variables (Gravetter & Wallnau, 1996).

Using descriptive statistics, the variance of each measure was examined by comparing the theoretical range of scores to the actual range of scores (Table 2). The preliminary analysis revealed that 45.5% of the measures had responses covering the full theoretical range. Two of the measures (e.g., SPMSQ and PPS) were designed to have restricted ranges due to exclusion/inclusion criteria, and the remaining scales had truncated ranges. Although there appears to be some issues with skewness and kurtosis, violations to the normality assumption may be less of an issue with larger samples (Mertler & Vannatta, 2005). Further analysis will be conducted, and if needed, data transformations (e.g., square root transformations if positively skewed or reflect and square root if negatively skewed) will be conducted.

Table N2: Psychometric Properties of Selected Measures

Measure	n (% missing)	M (SD)	α	Range		Distribution	
				Theoretical	Actual	Skew	Kurtosis
Patient							
SPMSQ	710(1%)	9.23 (0.93)		0-10	7-10	-.98	-.09
ADLI	711(<1%)	2.47 (2.23)	0.85	0-8	0-8	1.38	0.51
PPS	710(1%)	57.06 (10.95)		0-100	40-100	0.52	0.47
CES-D	702(2%)	3.01 (2.21)	0.71	0-10	0-9	0.46	-.68
HQLI	672(6%)	102.17 (17.43)	0.72	0-140	52-140	-.11	-.49
MSAS (distress)	717(0%)	20.49 (14.11)	0.83	0-100	0-78	0.91	1.05
MSAS (severity)	717(0%)	21.29 (12.92)	0.85	0-100	0-81	0.86	1.28
Caregiver							
SNI (total needs)	697(<3%)	57.42 (13.02)	0.89	17-85	17-85	-.07	-.49
SNI (total unmet needs)	717(0%)	1.26 1.26 (2.1)	0.74	0-17	2 0-12	5 2.5	7.24 7.24
Social Support	701(2%)	10.78 (1.73)	0.66	3-12	3-12	-1.88	3.77
SF-12 (PCS)	717 (0%)	48.53 (11.52)	n/a	X=50, SD=10	65.39- 13.47	-.927	-.479
SF-12 (MCS)	717 (0%)	46.69 (9.73)	n/a	X=50, SD=10	67.22- 13.13	-.141	-.233
CES-D	711(<1%)	2.93 (2.15)	0.71	0-10	0-10	0.53	-.38

Note. SPMSQ = Short Portable Mental Status Questionnaire; ADLI = Activities of Daily Living Index; PPS = Palliative Performance Scale; CES-D = Center for Epidemiological Studies Depression Scale; HQLI = Hospice Quality of Life Index MSAS = Memorial Symptom Assessment; SNI = Spiritual Needs Inventory; SF-12= Short Form Health Survey

Statistical power. Given the large number of predictor variables in this study, two types of analyses were conducted to ensure that the dataset (a) meets the minimum requirements to conduct multiple regression techniques and (b) has sufficient statistical power to generate a medium-sized effect. Using power analysis, with conventional values set at 0.05 for alpha and 0.80 for power (Cohen, 1988, as cited in Green, 1991) and including the 27 predictor and control variables in the calculation, it was determined that a sample size of 609 is needed to achieve a small effect size ($R^2 = 0.04$) and a sample of 178 is needed to achieve a medium-sized effect ($R^2 = 0.15$). A two-step rule-of-thumb procedure proposed by Cohen was also calculated to determine the minimum sample size for detecting a medium effect size for multiple correlations (e.g., $L = 6.4 + 1.65m - .05m^2$, $N \geq L/R^2$, with m = number of predictor variables) as well as partial correlations (e.g., $N \geq (8/R^2) + (m-1)$). Both analyses confirmed that the large sample size in the dataset ($N = 717$) has sufficient statistical power to examine the number of predictor and control variables in the model.

Correlational analysis. The final step in this analysis was to determine if there were any relationships among the variables. Failure to find significant relationships would be a good indicator that the selected variables may not be good predictors in predicting the best fit prediction line for the model. Therefore, a series of univariate analysis of variances (ANOVAs) and bivariate correlations were conducted between the independent variables and the dependent variable. Table 3 shows the intercorrelations among the continuous variables. Prior to conducting this analysis, some of the data was re-coded and total scores for the scales were computed (Table 4). The goal of this stage

was to find some relationships between the theoretical variables and the outcome variable.

Preliminary findings revealed that there were several theoretical variables from each of the stress domains, except the secondary stressor domain, that correlated with the outcome variable. For example, the two mediating variables (e.g., social support and fulfillment of spiritual needs) significantly correlated with the outcome variable (i.e., caregiver depression) ($r = -.32, p < .001$, $r = .38, p < .001$, respectively). Two of the objective primary stressors (e.g., patient QOL and symptom distress) also correlated significantly with the outcome variable ($r = -0.80, p < .05$, $r = 0.105, p < .01$, respectively). Based on these preliminary findings (a) further examination of the bivariate relationships will be analyzed and (b) next steps in the data plan will be to analyze the data using multivariate techniques.

Table N3: Summary of Intercorrelations among Independent and Dependent Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Patient																	
1. Age	--																
2. Gender	-.01 **	--															
3. ADLI	-.00	.13 **	--														
4. Pain	-.25 **	.06	.02	--	-												
5. SPMSQ	-.11 **	- .00	-.16 **	.03	--												
6. CES-D	-.11 **	.07	.06	.15 **	.04	--											
7. QOL	.18 **	- .03	- .08*	-.21 **	-.02	-.52 **	--										
8. MSAS (distress)	-.20 **	.05	.06	.27 **	.11 **	.48 **	-.65 **	--									
Caregiver																	
9. Age	.44 **	- .15 **	-.06	-.10 **	-.03	.00	-.03	- .02	--								
10. Gender	.12 **	- .53 **	-.07	-.01	.01	-.07	.10 **	- .07	- .09*	--							
11. Income	.01	.13 **	-.04	- .09*	.08	.01	-.02	- .02	- .10*	- .07	--						
12. Unmet spiritual	-.03	- .05	.07	.02	-.05	.06	-.02	.06	-.04	.05	.01	--					
13. Social Support	.06	.04	-.02	-.07	.07	-.01	.04	- .03	.15 **	- .07	.02	- .33 **	--				
14. SCID	- .08*	- .04	.00	.03	-.01	.09*	-.03	.05	.01	.02	- .11 **	.03	- .15 **	--			
15. PCS	-.11 **	.10 *	.01	.04	.07	.04	-.07	.06	-.19 **	- .06	.22 **	- .13 **	.12 **	- .16 **	--		
16. MCS	.12 **	- .01	-.09 *	- .08*	.00	- .09*	.07	- .13 **	.11 **	.05	.05	- .31 **	.19 **	- .16 **	- .13 **	--	
17. CES-D	-.12 **	- .05	.09*	.08*	- .08*	.08*	- .08*	.10 **	-.07	.02	- .08 *	.39 **	- .32 **	.21 **	- .13 **	- .59 **	--

Note. * $p < .05$, two-tailed. ** $p < .01$, two-tailed.

Table N4: Data Transformations

Variable	Data Transformation
MSAS-severity and distress scales	<p>Recoded severity and distress variables due to large amount of missing data.</p> <p>First part of the scale (part a) asks patients if they had a particular symptom. Patients who did not have the symptom were coded as -99 (missing). Part b (severity of symptom) and part c (distress of the symptom) were not asked if patients did not report the symptom. Since patients did not report certain symptoms, one could assume that these symptoms did not cause distress or the symptoms were not severe. It makes sense to recode the missing data, -99 to "0" so that these subjects could be included into the analysis.</p> <p>Conducted correlations between distress and severity scales, strong correlations were found ($r=.944$, $p<.001$), which means that these scales are not measure anything different; the questions are redundant. Plan to use the distress subscale score in the analysis because this variable is often used in the literature.</p>
Relationship variable	<p>Computed total distress score and severity score, 25 items</p> <p>Collapsed and recoded relationship variable: spouses/partners = 1; adult children = 2; 3 = other (siblings, parents, and friends). Recoded to dummy variables: spouse recode 1=spouse/partner; 0=not adult child/other; child recode, 1=Adult child; 0=not spouse/other</p>
Marital Status	<p>Collapsed and recoded marital variable: 0 = not married, 1 = married</p>
Living Arrangements	<p>Collapsed and recoded living variable: living alone =1; 2 =living with spouse and/or living with spouse and child; 3 = living with other;</p> <p>Recoded to dummy variables: living with partner 1 = living with spouse/partner; 0=not living with other/alone; living with other 1 = living with other; 0 = not living with spouse/alone</p>
Ethnicity	<p>Collapsed and recoded ethnicity variable: 0 = non-white; 1 = white</p>
Income	<p>Collapsed and recoded income: 1 = low income; 2=high income</p>
CES-D	<p>Computed total CES-D score, 10-items, patients and caregivers</p>
HQOL-14	<p>Computed total HQOL score , 14 items</p>
SNI	<p>Count total # no (count, 0=no), 17-itms, patients and caregivers</p>
SCID	<p>Count total # yes (count, 1=yes), 1-item-caregivers</p>
Received Support and Satisfaction	<p>Computed total support score for the 3-items</p>