

THESIS

PERCEIVED STRESS, CAREGIVER BURDEN, AND EMOTIONAL DISTRESS IN

CAREGIVERS OF HEAD AND NECK CANCER AND LUNG CANCER

Submitted by

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ABSTRACT

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Caregiving research focuses highly on the impact burden of care has on the mental health of caregivers (Nightingale et al., 2014; Northouse et al., 2012; Perz et al., 2011). However, little research focuses on how stress, as an independent construct contributes to the emotional distress caregivers of Head and Neck and Lung Cancer patients experience (Luchesia et al., 2016). This project aims to investigate the relationship between caregiver burden, perceived stress, and emotional distress (depression and anxiety) of caregivers of HNC and LC patients. Results revealed positive and significant relationships between predictor variables (perceived stress and caregiver burden) and emotional distress. Results further revealed higher perceived stress is indicative of higher caregiver burden. Additionally, preliminary results suggested the relationship between caregiver burden and emotional distress is moderated by the caregiver's level of perceived stress. Explanations and implications of all investigated relationships are discussed. This study highlights that in fact, perceived stress as a construct is important to explore when understanding the mental health needs of caregivers of Head and Neck and Lung Cancer patients.

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CHAPTER I

Introduction

The literature on the psychological well-being of cancer caregivers has shed light on the psychological challenges this population faces (Balfe et al., 2016; Given, 2004; Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt, & Van Den Bos, 1998; Northouse, Williams, Given, McCorkle, 2012; Perz, Ussher, Butow & Wain, 2011; Schott-Baer, 1993; Wood, Gonzalez & Barden, 2015). Often, caregivers of patients with cancer experience the same or more psychological distress (i.e. anxiety and depression) than the cancer patients they are caring for (Matthews, 2003; Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010; Wood et al., 2015). Informal caregivers, individuals who provide unpaid care, provide essential support to cancer patients. They accompany patients through their diagnosis, treatment, and recovery. Their role is multifaceted and constantly changing as the patient's medical and emotional needs change (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013). As a result of the demanding nature of cancer caregiving, caregivers have many psychological challenges (Romito et al., 2013). The challenges they face often are associated with lower quality of life and higher levels of distress (Printz, 2011).

Caregivers of patients with head and neck (HNC) and lung cancer (LC) are particularly understudied and underrepresented in the caregiving literature (Precious, Haran, Lowe, & Roger, 2012). These forms of cancer have a heightened impact on the psychological well-being of both the patient and the caregiver, specifically elevated levels of anxious and depressive symptoms (DeBoer et al., 1998; Frampton, 2001; Longacre, Ridge, Burtness, Galloway, & Fang, 2011;

Rogers et al., 2010). LC and HNC are considered some of the most traumatic forms of cancer because of their potential for physical disfigurement and difficulties with basic daily functions as a result of treatment (Nightingale, Lagorio, & Carnaby, 2014). The potential for facial disfigurement as well as the high risk for dysphasia (difficulty swallowing) associated with these cancers place unconventional demands on their caregivers (Nightingale et al., 2014). Caregivers may need to provide physical assistance such as: dressing and draining the surgical wound, tracheostomy care, enteral nutrition, and pain management (Fronczek, 2015). In addition to physical support, treatment effects may leave psychosocial issues that the caregiver must help the patient through. These may include: body image disturbances, and difficulty with clear communication (Baehring & McCorkle, 2012; Fronczek, 2015; Nightingale, 2014). The results of treatment therefore can also induce a great deal of stress in caregivers of HNC and LC. The stress they experience has the ability make the imbalance of care demands to resources even more challenging, especially if the caregivers themselves lack social support. The impact of these demanding tasks as a result of the caregiving role may include: impaired immune system functioning and increased risk for chronic diseases, as well as increased likelihood of mortality for the caregiver (Nightingale et al., 2014).

When the demands of the caregiving role exceed the emotional capacity of the caregiver, caregivers may experience caregiver burden (Given et al., 2004; Nijboer et al., 1998; Schott-Baer, 1993). The primary challenges associated with caregiver burden include sleep disturbances, psychological distress, financial distress, and potential cognitive impairment (Given et al., 2004; Kao & McHugh, 2004; Nightingale et al., 2014; Nijboer et al., 1998; Northouse et al., 2012; Schott-Baer, 1993; Wood et al., 2015). Early research conceptualized caregiver burden through the cognitive stress theory also known as the transactional model of

stress (TMS). This model highlights the importance of the relationship between environmental, psychological, physiological processes, and psychosocial factors that influence the experience of stress (Lazarus & Folkman, 1984). The key components of this model involved in the caregiving process are: stressors (effects of treatment on patient, financial, and employment), outcomes (caregivers' physical and psychological health), and potential mediators (social support and caregiver burden have been proposed) (Nijboer et al., 1998; Pearlin, Mullan, Semple, & Skaff, 1990). Therefore, to what extent the caregiver feels burdened by their role depends on the independent and dependent relationships of the TMS factors.

It is to be expected that the more stress caregivers of HNC and LC experience, the greater the perceived caregiver burden they will also experience, and consequently feel more psychological distressed. Caregivers have many reasons to be stressed, especially those of HNC and LC, whose caregiving role is multifaceted and highly demanding. However, the relationship of caregiver burden, perceived stress, and emotional distress has not been investigated among caregivers of HNC and LC patients. It is important to understand this relationship because stress is an integral part of these caregivers' experience. In order to design and implement psychological interventions that specifically target the emotional distress caregivers of HNC and LC experience, it would be helpful to better understand how stress might have an effect on the relationship between caregiver burden and emotional distress. If more is known about how the level of perceived stress of the caregiver influences the level of caregiver burden they experience, interventions can be targeted to reduce the amount of stress caregivers experience. In turn, interventions can more effectively lessen the impact that caregiver burden has on emotional distress, as well as potentially increase the level of care patients are receiving from their caregiver.

This project aims to look at the relationship between caregiver burden, perceived stress, and emotional distress (depression and anxiety) through self-report measures from caregivers of HNC and LC patients. More specifically, this study will investigate how these concepts are interrelated to provide evidence of how levels of perceived stress may potentially moderate the influence of caregiver burden on the emotional distress that caregivers of LC and HNC patients experience. Below, is a synthesis of the existent literature that sheds light about how caregiver burden is related to perceived stress and emotional distress among caregivers of HNC and LC patients.

Head and Neck Cancer and Lung Cancer Impact on Patients and Their Caregivers

Lung cancer is the primary cause of cancer death among men and women in the United States (American Cancer Society, ACS, 2015). Many LC patients also present with a primary or secondary diagnosis of HNC (Kuriakose et al., 2002; Siegel et al., 2012). Head and neck cancer accounts for approximately 300,000 deaths every year (Balfe et al., 2016; Lee, Lee, Wang, Chien, Fang, & Lin, 2017). LC and HNC are considered among the most “traumatic” forms of cancer (Frampton, 2001). Functional deficits within the HNC and LC population include increased pain, problems with eating and swallowing, dry mouth, and speech impairment. This leads to psychologically heightened levels of anxious and depressive symptoms, decreased quality of life, and decreased social interactions (DeBoer et al., 1998; Longacre et al., 2012; Rogers et al., 2009).

The main source of social support for LC and HNC patients comes from their caregivers (Balfe et al., 2016; Hérbert, Bravo & Prévile, 2000; Zarit, Reeve, Back-Peterson, 1980). The close relationship between patients and their caregivers provides insight into why as a patient’s

quality of life decreases, so does the caregiver's quality of life; and therefore caregivers too experience deficits in psychological health functioning alongside their patients (Balfe et al., 2016; Kim et al., 2016). Patients with HNC and LC are a group of cancer patients that are particularly understudied (Balfe et al., 2016; Kim et al., 2016; Ross et al., 2010). Moreover, there are a lack of studies investigating their caregivers when the patients are undergoing active treatment (Nightingale et al., 2014). HNC may be less common among individuals compared to other prevalent cancers, but much more severe in terms of physical disfigurement, basic life functioning, and distress. Therefore, caring for a HNC patient is extremely stressful and physically demanding on the caregiver (Fronczek, 2015). Consequently, the psychological functioning of caregivers of patients with LC and/or HNC is negatively impacted, with deficits that typically include emotional distress (depressive and anxious symptoms) (Longacre et al., 2012; Nightingale et al., 2014).

Caregiving Burden

An important shift in the cancer research has been to investigate the role of informal caregivers that provide care to cancer patients above and beyond that of the care they receive in the hospital. In fact, 83% of overall caregivers are informal caregivers (Family Caregiver Alliance, 2005). One of the most common conditions for providing informal caregiving is cancer (Wood et al., 2015). The National Alliance for Caregiving estimates that 4 million individuals are caring for an adult with cancer. This is 8% of all U.S. caregivers. In contrast to formal caregivers who include nurses, doctors, or other paid individuals, informal caregivers are typically family members or friends (Wood et al., 2015). Caregiving involves emotional and/or physical care tasks in response to a person with a chronic illness or disease. Some caregivers

may see their role as a challenge, but a positive one. Others may perceive it as a burden. When the care tasks are perceived as negative, it is referred to as caregiver burden (Nijboer et al., 1998; Schott-Baer, 1993).

Various definitions are offered in regards to caregiver burden, as there is no universal definition (Romito et al., 2013). There are, however, common themes involved in much of the research on caregiver burden. Consensus within the research is that caregiver burden involves a disruption or an imbalance of demands that are relative to a caregiver's emotional and physical state of being (Given et al., 2004; Nijboer et al., 1998; Schott-Baer, 1993). Reactions to the caregiving role may impact the caregiver's life psychologically, financially, physically, and socially. Therefore, some research makes the distinction between objective burden (e.g., disruption to daily schedule, negative effects on finances, physical health decline) and subjective burden (how much caregiver perceives a situation to be negative) (Wood et al., 2015).

The trajectory and intensity of caregiving is relative to the type of illness that the recipient of care is diagnosed with. In a study done by Nightengale, Lagorio, and Carnaby (2014) on caregivers of HNC patients, caregiver burden is associated with greater patient functional disability, depression, and cognitive impairment. Typically, the more confining the care tasks for the caregiver, the more burden is perceived (Nijboer et al., 1998). Caregiving for cancer patients increases over time as their cancer progresses (Schott-Baer, 1993). It is also a type of caregiving that can be extremely demanding both physically and emotionally. Personal tasks (e.g., feeding/washing) are perceived as more difficult and burdensome than non-personal tasks (e.g., grocery shopping). As a result of the facial disfigurement often seen in HNC, caregivers of these individuals have a higher emphasis on personal tasks. Providing emotional support to patients has been shown however to be the most burdensome task (Nijboer et al., 1998).

Research in caregiving has found both positive and negative aspects that affect the caregiver, both mental and physical health. In terms of mental health, outcomes that are often looked at as a result of caregiving burden include: depression, anxiety, and overall emotional distress (Nijboer et al., 1998). Many investigations have reported that caregivers have higher levels of perceived stress, anxiety, and depressed mood than non-caregivers (Okamoto & Harasawa, 2009; Vitaliano, Strachan, Dansie, Goldberg, & Buchwald, 2013). However, it should also be mentioned that not all studies in the area of caregiving have found that caregiving is associated with greater distress (Vitaliano et al., 2013). Vitaliano and colleagues (2013) mention that there are some studies that report there is not a difference between caregivers and non-caregivers in terms of distress, where as some other studies even find caregiving provides certain benefits to caregivers, or they find a mixed report of benefits and stressors. Some positive effects of the caregiving process have also been identified in the literature that would serve as a protective factor against the “burden” of caregiving. These positive aspects of caregiving include: recognition of positive experiences (love, affection, meaning, commitment). Positive effects may increase pride and self-worth in caregivers and have the power to define an identity and involvement in society (Nijboer et al., 1998).

Ross et al. (2010) suggests that devoting more time to caregiving may have negative objective effects (e.g., time, finances, stress). The increased time with the patient may also lead to better adaptation of the caregiver role, which in turn may lead to intrinsic rewards. The amount of caregiver burden therefore has been found to be predicted by: a lack of family and social support, increased physical care needs of the patient, unmet health informational needs, disrupted schedules, and financial issues (Nijboer et al., 1998). With that being said, the vast

majority of the literature on the caregiving population provides evidence for the positive relationship between caregiver burden and emotional distress.

Caregiver Burden and Stress

For many informal caregivers, there is a need to find resources to better cope with the burden of caregiving. In fact, in a study surveying 1,480 caregivers, 78% reported needing help finding more resources to cope (NAC and AARP, 2009). A lack of information and understanding likely leads to worry and stress. Certain studies investigated various factors that might serve as predictors of caregiver burden, and potentially serve also as protective factors. In a study looking at the unmet needs of cancer caregivers, the most commonly reported unmet needs were: (a) fear of recurrence of cancer; (b) reducing stress in the person they are caring for; and (c) increasing understanding of the experience of the person with cancer that they are providing care for (Girgis et al., 2013). Research has found that for illnesses like cancer, stress may build as a result of the caregiver feeling helpless, observing the illness progress and not being able to do anything about it (Luchesi et., 2016; Nijboer et al., 1998). Perceived stress is the process of evaluating whether demands are exceeding resources by the person who is experiencing a particular situation and to what degree this situation is appraised as stressful. The level of perceived stress has been found to be associated with both anxiety and depression (Spada, Nikcevic, Moneta, & Wells, 2008). Caregivers are a unique population that experience a significant more amount of stress than individuals who are not a primary caregiver (Luchesi et al., 2016).

To understand the relationship between stress and caregiver burden, Nijboer and colleagues (1998) proposed to utilize the cognitive stress theory. The cognitive stress theory, developed by Lazarus and Folkman (1984), states that contextual elements as well as perceptions

of a situation play a major role on how stressful a situation is perceived to be. The stress process begins when an event or situation is seen as an imposition (Spada et al., 2008). For this population, the stressful situation is caregiving for a patient suddenly diagnosed with cancer. This model of stress states that it is the relationship between environmental, psychological, physiological processes, and psychosocial factors that influence an individual's experience of stress (Lazarus & Folkman, 1984). All individuals appraise events differently, which makes some more vulnerable to negative stress-related outcomes. This model of stress has frequently been used in caregiving research, because caregiving is relative to a given illness and because no two caregiver's experiences are the same (Gaugler, 2007; Luchesi et al., 2016; Nijboer et al., 1988; Thomas & Borrayo, 2011).

Following Pearlin and colleagues (1990) there are three key components of the cognitive stress theory said to be involved in the caregiving process. These are: stressors, outcomes, and potential mediators. Stressors for caregivers refer to the patient's physical and psychological health, as well as the associated care tasks. Outcomes refer to the caregiver's physical and psychological health, while social support may be conceptualized as a potential mediator. Owensworth, Henderson, and Chambers (2010) found that for caregivers of patients with brain tumors and other cancers who had greater social support and more resources had greater caregiver psychological well-being. In conjunction, lack of social support may lessen the ability for caregivers to cope with stressors and therefore may increase the likelihood of burden, anxiety, fatigue, and quality of life (Gaston-Johansson, Lachica, Fall-Dickson, Kennedy, 2004). Therefore, there is evidence to suggest that more stressful situations, without the ability to cope, add to the negative effects caregiver burden has on the caregivers.

There are certain caregiving demographics that are especially at high risk for experiencing negative effects of caregiver burden and stress. Schrank and colleagues (2016) highlight that research has supported the majority of informal caregivers are women. Female caregivers report higher levels of burden, stress, anxiety, and fatigue. They also report lower levels of self-esteem as a result of their caregiver role. Younger age has also been associated with greater distress (Ross et al., 2010). This is especially true for female daughters who report the most cancer caregiving stress (Ross et al., 2010; Teixeira, 2013).

Medically and financially underserved caregivers are another population at high risk for experiencing the negative effects of caregiver burden and stress. Research has supported that individuals lower in SES experience more caregiver burden. Lower education level and lower family income is associated with higher perceived stress (Nijboer et al., 1998; Luchesi et al., 2016). Gaugler and Given (2008) have found evidence that as a result of being financially underserved, out of pocket expenses, and lost wages are all linked to increased emotional distress. Furthermore, higher levels of care-related burden were associated with higher levels of perceived stress (Luchesi et al., 2016). These variables are likely to have a large impact on the levels of caregiver burden and perceived stress experienced by underserved caregivers.

Caregiver Distress

As a result of the significant negative impact that cancer has on patients and their caregivers, research has increased since the 1990s related to how the quality of life of cancer patients and their caregivers is affected (Wood et al., 2015). Quality of life (QOL) is a common variable measured to assess how cancer might be impacting the lives of these individuals. Overall QOL is a sense of well-being individuals have in various aspects of their lives and there are many factors that play into this umbrella term (Wood et al., 2015). In a study done by Perz,

Ussher, Butow, and Wain (2011), 20-30% of caregivers of cancer patients were found to be at high risk for psychiatric morbidity, a level of distress that is significantly higher than that found in community populations. They also found that unmet needs and greater burden of care are associated with distress. Ross et al. (2010) found that in a population of caregivers for head and neck squamous cell carcinoma, 21.6% of caregivers reported moderate emotional distress and 15.9% reported high emotional distress.

Distress as a result of being a caregiver may manifest through symptoms of anxiety, depression, helplessness, burden, and fear (Given et al., 2004). The literature supports that distress is most often operationalized as a combination of depression, burden, or anxiety (Given et al., 2004; Longacre et al., 2012; Perz et al., 2011). More often, distress is measured as depression and anxiety symptoms; although similar to caregiver burden there is variation within the literature regarding how to operationalize distress. Research among caregivers suggests that family members of patients with cancer experience distress as a result of caregiving roles, and the distress continues over time.

Fronczek (2015) found that caregivers of HNC patients had more concern about the re-occurrence of the cancer than the patients themselves. The high levels of fear correlate with emotional distress and anxiety. This study found that the coordination of care was seen as a large challenge. In particular, these caregivers verbally reported a strong need to feel prepared to deal with the aspects of caregiving. The amount of information presented to them was overwhelming and created feelings of doubt. In a study done by Balfe and colleagues (2016), six key triggers of emotional distress were found in a population of long term caregivers for HNC. These included: understanding and fear of the illness, lifestyle restrictions and competing demands, facial disfigurement, financial problems, comorbid health problems, and witnessing suffering. In order

to deal with the burden of caring for someone with HNC, the caregivers in this study indicated that support was particularly valuable to them. The above findings are consistent with Gaugler and colleagues (2008) that found that social support helps to protect caregivers from undue stress and tension in family relationships. Therefore, the research suggests that this population of caregivers is a high risk population for experiencing emotional distress, among other psychological challenges.

Current Study

The literature above has highlighted the importance of better understanding how mental health and well-being is affected among caregivers of cancer patients, but particularly that of caregivers of HNC and LC patients. Research in this area often considers the independent influence caregiver burden has on the mental health of the caregiver, namely on their emotional distress and quality of life (Nightingale et al., 2014; Northouse et al., 2012; Perz et al., 2011). Additionally, the extreme demand these two types of cancers place on the patient and consequently on their respective caregivers create significant stress as well as higher levels of emotional distress (Fronczek, 2015; Gaugler et al., 2008).

Less research is available to understand the independent effect of perceived stress on emotional distress among caregivers of HNC and LC patients. In addition, there is a lack of evidence on how the appraisal of stress might independently contribute to the levels of caregiver burden among these caregivers. Although the effects of perceived stress has mostly been investigated among caregivers of older adults, it has scarcely investigated caregivers of HNC and LC patients. In part, it may be that there are elements of perceived stress implied in measures of caregiver burden. The relationship between caregiver burden and perceived stress in regards to cancer caregiving is sparse and almost non-existent in the population of caregivers of HNC and

LC patients. Limited research suggests there is an association between perceived stress and caregiver burden that indeed predicts caregivers' level of depression (Luchesia et al., 2016).

This project aims to investigate the relationship between caregiver burden, perceived stress, and emotional distress (depression and anxiety) of caregivers of HNC and LC patients. More specifically, this study will investigate how these concepts are interrelated to provide evidence of how levels of perceived stress may potentially moderate the influence of caregiver burden on the emotional distress that caregivers of LC and HNC patients experience. The following research questions will be included:

1. Primary Research Question: (a) Does perceived stress predict emotional distress experienced by caregivers of patients with head-and-neck cancer (HNC) and lung cancer (LC)?; (b) Does perceived caregiver burden among these caregivers also predict emotional distress they experience?; (c) Does perceived stress predict caregiver burden?
2. Secondary Research Question: (a) Is the relationship between perceived caregiver burden and emotional distress moderated by the caregiver's level of perceived stress?

Hypotheses:

1. Hypothesis 1: Levels of perceived stress will be significantly and positively associated with caregiver burden among caregivers of LC and HNC.
2. Hypothesis 2: Caregiver burden among caregivers of LC and HNC patients will significantly and positively predict emotional distress (depression and anxiety symptoms) above and beyond caregiver characteristics (e.g. age, gender) and health care access variables (e.g. income, insurance).
3. Hypothesis 3: Perceived stress will positively and significantly predict emotional distress.

4. Hypothesis 4: The relationship between perceived caregiver burden and emotional distress among caregivers of LC and HNC patients will be further moderated by the caregiver's perceived stress, specifically, the relationship between caregiver burden and emotional distress will be strengthened by perceived stress.

CHAPTER II

Method

This study is part of a larger ongoing randomized control trial (RCT) study titled “A Stepped Care Intervention to Reduce Disparities in Mental Health Services among Underserved Patients and Caregivers with Lung and Head and Neck Cancer,” (Evelinn Borrayo, Principal Investigator). The aim of the larger study is to conduct a comparative effectiveness study to assess the effectiveness of a stepped care intervention to an enhanced usual care condition on reducing emotional distress and improving coping skills among 440 lung cancer and head and neck cancer patients and 440 caregivers randomly assigned to one of the conditions. The primary outcomes for the larger study are: distress (depression and anxiety symptoms), and coping self-efficacy. The secondary outcomes are: health related quality of life, perceived stress, and caregiver burden. This proposed study, will not focus on the intervention, but will assess instead the relationship between caregiver burden, distress, and perceived stress through self-report surveys from the caregiver population recruited for RCT at baseline.

Participants and Procedure

Participants. The estimated number of participants for this study will include 150-160 caregivers of head and neck and/or lung cancer patients (see power analysis page 20-21). Sociodemographic information and complete measures will be obtained from the caregiver population of the larger study. All caregivers meeting inclusion criteria will be included in this study. The inclusion criteria for this study are: caregiver of a newly diagnosed lung cancer and/or head and neck cancer patient, over 18 years old, and English and/or Spanish speaking. The

exclusion criteria are as follows: individuals who do not speak Spanish or English, caregivers of patients who refuse treatment at one of the hospital sites, individuals with cognitive or personality impairment, suicidal ideation, or intoxication that may interfere with their ability to consent or participate in the study, and individuals from vulnerable populations (e.g. inmates, homeless, pregnant women, and those with auditory impairment).

Procedure. Approval for this study was obtained through the Colorado Multi-Institutional Review Board at the University of Colorado Denver for the larger study, “A Stepped Care Intervention to Reduce Disparities in Mental Health Services among Underserved Patients and Caregivers with Lung and Head and Neck Cancer” (COMIRB # 16-2621). Therefore, the procedural nature of this comparison study follows the procedure for the larger study. Participants will be recruited from four hospitals: the Denver Health and Hospital Authority (DHHA), the Cancer Centers of Colorado at Saint Joseph Hospital, National Jewish Health, and from Saint Mary’s Hospital and Medical Center. Each hospital has a trained Site Research Coordinator responsible for the recruitment and consent of study participants. The recruitment procedures are compliant with current HIPAA regulations. Authorization (via informed consent) will be obtained by each of the hospital’s Site Coordinators in a private and comfortable medical consultation room per site.

To recruit caregivers of LC and HNC patients, we will first identify newly diagnosed LC and HNC patients (within a month of recruitment date from the date of 1st visit oncology, ENT, or radiation clinic visit/consultation upon pathologic tissue diagnosis) when pre-screening for all cancer patients. The various methods through which we will recruit patients are (a) monthly audit of electronic medical records from all three hospitals to identify patients diagnosed with LC or NHC within 30 days prior to the audit, as well as (b) weekly attendance to cancer tumor

boards to identify newly diagnosed patients, and (c) daily review of clinic visits to identify all LC and HNC patients in the oncology clinic, ear-nose-and throat (ENT) clinic, and radiation oncology clinic/unit at each hospital.

Caregivers will therefore be identified through the patients they care for. After patients and caregivers are identified, patients and caregivers will be informed and invited to participate in the study following the procedures listed below:

1. Site coordinators will arrange an information meeting with physician and patient to introduce the study and invite the patient (and caregiver if present) to participate.
2. If the patient's caregiver is not present, the Site Coordinator will ask for the patient's agreement to contact their caregiver via phone and invite them to participate in the study. The patient and caregivers will be informed that the "dyad" participation is not required and that one of them may still participate if the other does not wish to.
3. For caregivers who are absent at the time of the patient's recruitment, the Site Coordinator will arrange to meet the caregiver to inform and invite them to participate in the study.

When patients and caregivers are identified and indicate they wish to participate in the study, they will be consented to participate. Participants will be provided with an electronic informed consent form to sign and will receive a hard copy for their records. All patients and caregivers who agree and consent to participate in the study will complete the "baseline measures" and will receive a \$25 incentive.

Participants will complete baseline measures for caregivers. The measures of interest for this study are: the socio-demographic questionnaire, the Perceived Stress Scale (PSS-10 item adapted for low-literacy populations), the Zarit Burden Interview (ZBI), and the PROMIS measures of

emotional distress (anxiety and depression adult versions). The preferred method of completing the measure will be to provide participants a link to complete the measures online. If participants do not have access to a computer, or are unable to complete the measures online, they will be provided a paper copy of the measures. If participants are unable or unwilling to fill out the measures online or via paper copy, Site Coordinators will assist them in completing the measures at the given hospital site. Data will automatically be stored in REDCap if participants complete the measures online or in person with a Site Coordinator. If participants complete the paper version, the research team will input participant data into the online REDCap version.

Instruments

Demographic Characteristics. Participants will be assessed at baseline (recruitment). Questions pertain to age, sex, income, education level, primary spoken language, primary language read, insurance status, cognitive functioning, past diagnosis and treatment of any psychiatric disorders (see appendix B).

Perceived Stress. The Perceived Stress Scale (PSS) is a 10-item scale, scored on a 5-point Likert type scale to assess the degree to which an individual perceives their situation to be stressful. The specific 10-item scale for this study has been adapted for low-literacy populations. The PSS's internal consistency reliability ranges from .80 to .89 and has been used among caregivers of cancer patients (Kessler et al., 2014; Lee, 2012;) (see appendix E).

Distress. Patient-Reported Outcomes Measurement Information System (PROMIS) measures will assess distress in caregivers. Two separate PROMIS measures will be used to measure distress: PROMIS anxiety (form 8b) and PROMIS depression (form 8b). Anxiety items measure items such as fear, anxious misery, hyperarousal, and somatic symptoms related to

arousal. Depression items measure negative mood, views of self, social cognition, decreased positive affect and engagement. PROMIS measures have calibrated items that are well-defined and validated. PROMIS measures have been used in a variety of populations, including cancer and low-literacy populations. Alpha ranges between .86-.97 for anxiety and depression measures (see appendices C & D).

Perceived Caregiver Burden. The Zarit Burden Interview measure is a 22-item scale that assesses the level of burden experienced by principal caregivers. The ZBI measures to what extent a caregiver perceives their responsibilities and role as burdensome. The short version (i.e. ZBI-12) will be used for this study as it has been successful with family caregivers in oncology (Shrank et al., 2016). The two domains of caregiver burden assessed are personal and role strain. This scale has been shown to reflect good internal consistency (Cronbach's alpha: .85-.89) (Shrank et al., 2016) (see appendix F).

CHAPTER III

Results

Missing Data and Tests of Assumptions

To look at the distribution of missing data, Little's Missing Completely at Random (MCAR) test was conducted with the variables of interest (Little, 1998). The primary MCAR revealed a significant test $\chi^2(69, N = 142) = 106.320, p = .003$, suggesting that the data were not missing at random. Missing data has the potential to bias estimation of the data because statistical procedures are designed with the assumption that data is not missing. Systematic missing data weakens the generalizability of the results and reduces statistical power as a result of the loss of information (Dong & Peng, 2013). Upon inspection of the missing data, income was missing 9.9% of participant responses and hours of care was missing 12.0% of participant responses. All of the other variables of interest were missing no more than 2.1% of responses (Dong & Peng, 2013). Because of the close connection between income and health insurance as a reflection of access to care and other resources, the decision was made to drop income as a variable of interest and instead only use health insurance (DeNavas-Walt, 2005). Although hours of care had a high amount of missing values, hours of care has been shown to impact caregiver psychological well-being (with greater numbers of care associated with lower well-being) and therefore it was deemed to be an important variable to maintain (Flaskerud, Carter, & Lee, 2000). A second MCAR was conducted, removing income and maintaining hours of care. The secondary MCAR revealed a non-significant test, $\chi^2(44, N = 142) = 44.855, p = .436$, suggesting the data was missing at random. Therefore, cases with missing data were dropped listwise from the analyses (Dong & Peng, 2013).

The variables were also examined for violations of linearity, homoscedasticity, normality, and independence. Linearity was assessed by plotting the residuals of the linear regression against each predictor variable (perceived stress and caregiver burden). Scatterplots revealed a linear relationship was supported for caregiver burden and emotional distress. Scatterplots revealed there was a curvilinear relationship between perceived stress and emotional distress. This curvilinear relationship was supported by a significant Tukey test (3.26, $p < .001$). To address the issue of a curvilinear relationship, a polynomial regression was conducted with perceived stress and the dependent variable.

To test for homoscedasticity, plots revealed there was a non-constant residual variance in regards to caregiver burden. Specifically, as caregiver burden increases, the prediction of emotional distress had greater variance. A “non-constant variance score test” was conducted to confirm the visual inspection of the data ($\chi^2=3.58$, $p = .05$). Because the test was significant at (.05), a heteroscedasticity-corrected covariance matrix was used. The coefficient estimates remained the same, indicating that the overall conclusions of the model remain the same. Therefore, the violation of homoscedasticity did not impact the model to a degree deemed to impact the analyses.

In order to further assess the distribution of the data, plots were used to regress the dependent variable (emotional distress) on the predictor variables (perceived stress, caregiver burden) and the control variables (age, gender, language, insurance, hours of caregiver). The first scatterplot regressed the dependent variable (emotional distress) on caregiver burden. Visual inspection revealed the data was normally distributed. Tests of skewness and kurtosis confirmed this analysis (skewness and kurtosis values were within the acceptable range (± 2) (George & Mallery 2010). The second scatterplot regressed the dependent variable on perceived stress.

Visual inspection revealed the data was normally distributed. Tests of skewness and kurtosis confirmed this analysis (skewness and kurtosis values were within the acceptable range (± 2) (George & Mallery 2010).

In regards to multicollinearity, no two scales were highly correlated (Thompson, Kim, Aloe, Becker, 2017) (See Table 2). There is inconsistency in the field as to an appropriate cut-off for scales being highly correlated. Thompson et al. (2017) suggest for two predictor models a cut-off of .80 is acceptable. In our findings, correlations between variables ranged from .43 to .64. This indicates that the values for multicollinearity were within the acceptable range.

Descriptive Statistics

Descriptive statistics were conducted on all variables entered in the regression analyses to acquire frequencies (Table 1) and means, standard deviations, and Pearson's r correlations (Table 2). The internal consistency for all scales was also assessed using Cronbach's alpha reliability (see Table 2). Emotional distress (PROMIS Depression, Cronbach's alpha = .93; PROMIS Anxiety Cronbach's alpha = .94), caregiver burden (ZBI, Cronbach's alpha = .88), and perceived stress (PSS, Cronbach's alpha = .85) all demonstrated adequate internal consistency reliability, consistent with the literature. Further, correlational analyses between the dependent variable and the predictor variables revealed that all scales were moderate to moderately strongly correlated and significant at the ($p < .001$) level, although not too strongly correlated to risk multicollinearity.

Caregiving research often conceptualizes emotional distress or psychological distress as combined symptoms of anxiety and depression that are integral to the caregiving experience (Longacre et al., 2012; Matthews, 2003; Nightingale et al., 2014; Ross et al., 2010; Wood et al., 2015). Therefore, this study justified combining the raw scores from PROMIS Anxiety and

PROMIS Depression measures to better reflect the literature and the experience of caregivers. PROMIS measures have varying scoring options, with the preferred method converting raw scores to T-scores. Due to the combined nature of anxious and depressive symptoms, the raw scoring option was used for this study. In order to have accurate raw scores, scores could not be included if they were missing values. Therefore, any participant that had a missing item on PROMIS Anxiety or Depression was dropped from the analysis. A total of 30 participants were dropped due to missing data.

Inferential Statistics

As stated under the first hypothesis, levels of perceived stress were significantly and positively associated with caregiver burden among caregivers of HNC and LC ($r = .78, p < .000$). That is, caregivers who perceive greater level of stress also report greater level of caregiver burden associated with their role. The second hypothesis that caregiver burden will significantly and positively predict emotional distress (depression and anxiety symptoms) above and beyond caregiver characteristics (control variables) was also supported, ($B = .76, p < .000$). This means, that when holding constant variables (e.g. sex, age, hours of care, etc.) that may impact the relationship between caregiver burden and emotional distress, caregivers who report greater levels of caregiver burden also report greater levels of depression and anxiety symptoms.

The third hypothesis was that perceived stress will positively and significantly predict emotional distress. Linear regression models assume that the relationship between two variables is linear, that is for every one unit increase in an independent variable, there should be a similar increase in the dependent variable. However, not all relationships are linear in nature, in some cases a curvilinear relation provides a better fit to the data. When a linear line does not best fit the data, a polynomial regression can be used. In a polynomial regression, the regression

coefficients remain the same, they just have an added feature. Instead, the coefficients are transformed to another degree. A polynomial regression uses the model coefficients and models them to the “*n*th degree,” with the squared model reflecting a quadratic polynomial and a cubed model reflecting a cubic polynomial (e.g. X becomes X^2 or X^3).

The relationship between perceived stress and emotional distress was found to be curvilinear, or there was a skew in the distribution of the data (see Scatterplots). This meant that as perceived stress increases, emotional distress increases drastically, but only above a specified level of perceived stress. To account for the curvilinear relationship between perceived stress and emotional distress, a polynomial regression was conducted. The polynomial regression was significant at the quadratic level, ($t = 3.84, p < .00$). It was not significant at the cubic level indicating the quadratic level is the best fit model. This indicated that the effect of perceived stress on emotional distress increases as stress increases.

Using the quadratic model as the best fit, the first model regressed emotional distress on the control variables (gender, age, language, insurance, hours of care). This model revealed that 16.5% of the variance in emotional distress could be accounted for by the control variables, ($F(7, 113) = 3.194, p < .05$). The second model added the predictor variables (caregiver burden and perceived stress, including the quadratic polynomial). The R^2 increased to 68% revealing that caregiver burden and perceived stress accounted for 51.5% of the variance in emotional distress, ($F(10, 110) = 23.67, p < .000$). This means that over 50% of reported emotional distress experienced by caregivers of HNC and LC is explained by caregiver’s reported perceived stress and levels of experienced caregiver burden.

The fourth hypothesis predicted that the relationship between caregiver burden and emotional distress among caregivers of HNC and LC patients will be further moderated by the

caregiver's perceived stress, specifically the relationship between caregiver burden and emotional distress will be strengthened by perceived stress. For the moderation model (model 3), an interaction term was created using caregiver burden and both the linear and quadratic specifications of perceived stress. The interaction term was significant for the first order polynomial, indicating that when holding constant all control variables (i.e. age, gender, language, insurance, hours), the effect of caregiver burden on emotional distress is dependent on the level of perceived stress of the individual, ($F(12, 110) = 20.64, p < .05$), $R^2 = .6963$. However, the interaction term for the second order polynomial (perceived stress squared) which is a better representation of the curvilinear data, was not significant.

Because the interaction term between perceived stress and caregiver burden was significant, the interaction was probed using the techniques outlined by Preacher, Curran and Bauer (2006). The interaction was probed with low and high levels of perceived stress to determine if the effect of perceived stress on caregiver burden was significant only when perceived stress was high. The results of Model 4 revealed that when perceived stress is high, caregiver burden has a substantial effect on emotional distress but when perceived stress is low, caregiver burden does not have a substantial effect on emotional distress (a one unit increase in caregiver burden is associated with a 1.77 unit increase in emotional distress when perceived stress is high, $p < .000$). More specifically, the effect of caregiver burden on emotional distress is dependent on perceived stress when perceived stress is one standard deviation below, at, and above the mean. Scores on perceived stress range from 0 to 40. When perceived stress is lower than a reported score of 13, the effect of caregiver burden on emotional distress is not significant. By probing the interaction, the model was improved by a clearer relationship among variables that indicated emotional distress significantly increases as perceived stress increases.

CHAPTER IV

Discussion

This study aimed to investigate the relationship between caregiver burden, perceived stress, and emotional distress (depression and anxiety) in caregivers of HNC and LC patients. More specifically, this study explored how these concepts are interrelated to provide evidence of how levels of perceived stress may potentially moderate the influence of caregiver burden on the emotional distress that caregivers of LC and HNC patients experience. Perceived stress was assessed by examining to what degree an individual perceives their life to be stressful in the last month. Results confirmed positive and significant relationships between hypothesized predictors (perceived stress and caregiver burden) and emotional distress. Results also indicated that higher perceived stress is indicative of higher caregiver burden.

The specific way in which perceived stress relates to caregiver burden and emotional distress was also explored. The relationship between caregiver burden and perceived stress in regard to caregiving for a cancer patient is sparse and almost non-existent in the population of caregivers of HNC and LC patients. Limited research suggests there is an association between perceived stress and caregiver burden that indeed predicts caregivers' level of depression (Luchesia et al., 2016). Results indicated that the relationship between caregiver burden and emotional distress is moderated by the caregiver's level of perceived stress. That is, the impact that caregiver burden has on caregiver's emotional distress is dependent on the levels of perceived stress reported by a caregiver. The literature does highlight that stress is an integral part of caregivers' experience; therefore this finding provides further support from past cancer

caregiving literature that the demands related to caring for a patient create significant stress as well as higher levels of emotional distress for caregivers (Fronczek, 2015; Gaugler et al., 2008). This result adds to the literature that is similar for caregivers of other cancer patients. However, it was also determined that the relationship between perceived stress and emotional distress is not linear; meaning that as perceived stress increases, emotional distress increases only relative to the level of perceived stress. Therefore, further exploration is needed to find a best model fit for this variable.

Caregiver Burden and Perceived Stress

This study aimed to fill in the gap in the literature regarding the relationship between caregiver burden and perceived stress among caregivers of LC & HNC patients. Perceived stress was positively related to caregiver burden. This result is consistent with one of the hypotheses of the current study and support past research findings about the association between caregiver burden and stress. Other studies have found that stress is an integral part of the caregiving relationship, where both influence each other (Gaugler, 2007; Lazarus & Folkman, 1984; Luchesi et al., 2016; Nijboer et al., 1998; Thomas & Borrayo, 2011). Cancer research has not, however, investigated this relationship as thoroughly and explicitly in regards to caregivers of HNC and LC. Therefore, this finding adds new information about the relationship between perceived stress and caregiver burden in caregivers of patients with HNC and LC.

Throughout the field, the integrative relationship between stress and caregiver burden has been conceptualized from a cognitive stress theory framework, first proposed by Lazarus and Folkman (1984). Caregiver burden involves a disruption or an imbalance of demands that are relative to a caregiver's emotional and physical state of being (Given et al., 2004; Nijboer et al., 1998; Schott-Baer, 1993). Contextual elements as well as perceptions of a situation play a major

role on how stressful a situation is perceived to be. The stress process begins when an event or situation is appraised as an imposition (Spada et al., 2008). For this population of HNC and LC caregivers, the stressful situation is caregiving for a patient diagnosed with cancer who is about to undergo very physically and psychologically demanding treatment. This model of stress states that it is the relationship between environmental, psychological, physiological processes, and psychosocial factors that influence an individual's experience of stress (Lazarus & Folkman, 1984). Research has shown there are specific components of the cognitive stress theory involved in the caregiving process: stressors, outcomes, and potential mediators (Pearlin et al., 1990).

Caregiver Burden and Emotional Distress

Caregiver burden was hypothesized to significantly and positively predict emotional distress above and beyond caregiver demographic characteristics and health care access variables (i.e. insurance). Distress as a result of being a caregiver may manifest through symptoms of anxiety, depression, helplessness, burden, and fear (Given et al., 2004). The results of the hierarchical regression supported this hypothesis and is consistent with the literature on the impact caregiving has on psychological symptoms (i.e. depression and anxiety) (Fronczek, 2015; Given et al., 2004; Nightingale et al., 2014; Northouse et al., 2012; Perz et al., 2011). Often, caregivers of patients with cancer experience the same or more psychological distress (i.e. anxiety and depression) than the cancer patients they are caring for (Matthews, 2003; Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010; Wood et al., 2015). The high levels of fear correlate with emotional distress and anxiety. Therefore, the research suggests that this population of caregivers is a high risk population for experiencing emotional distress, among other psychological challenges such as decreased quality of life. Other challenges associated with caregiver burden include sleep disturbances, psychological distress, financial distress, and potential cognitive

impairment (Given et al., 2004; Kao & McHugh, 2004; Nightingale et al., 2014; Nijboer et al., 1998; Northouse et al., 2012; Schott-Baer, 1993; Wood et al., 2015).

Perceived Stress and Emotional Distress

This study was especially interested in understanding the independent effect of perceived stress on emotional distress among this population of caregivers. Perceived stress as a predictor of emotional distress has typically been investigated among caregivers of older adults. It has not been investigated in caregivers of HNC and LC patients. The hypothesis that perceived stress will positively and significantly predict emotional distress was supported, ($F(1, 139) = 32.23, p < 0$). This means that as perceived stress increases in caregivers of HNC and LC patients, emotional distress will increase as well.

A further look at the residuals data (or the difference between the observed value and its theoretical value) also revealed that the relationship between perceived stress and emotional distress was curvilinear, meaning there wasn't a consistent increase in emotional distress as caregiver burden increased. This relationship probed the question, what is the specific effect of perceived stress on emotional distress? The results of this study indicate that the effect of perceived stress varies. Specifically, perceived stress's effect is greater at higher levels. In contrast, it has a very small effect on emotional distress at lower levels.

This study was one of the first to explore this independent relationship and therefore further studies are needed to confirm the relationship with this population of caregivers. These above results, in combination with the lack of research on the relationship between perceived stress and emotional distress in caregivers of HNC and LC, mean that more research is needed.

Our findings suggest there may be something unique about the relationship between perceived stress and emotional distress in this population that is different from older adults and other types of cancer caregiving.

Caregiver Burden, Perceived Stress, and Emotional Distress

In addition to the independent effects of caregiver burden and perceived stress on emotional distress, a question in this study was: is the relationship between caregiver burden and emotional distress moderated by the caregiver's level of perceived stress? The goal was to understand how perceived stress, caregiver burden, and emotional distress are interrelated and impact a caregiver's experience. Preliminary results indicated the effect of caregiver burden on emotional distress is dependent on certain levels of perceived stress. A hierarchical regression revealed a significant interaction between caregiver burden and perceived stress, indicating there are elements of the perceived stress scale that are not accounted for in caregiver burden and influence the effect caregiver burden has on emotional distress.

Because caregiver burden scales measure the construct in regards to the appraisal of the role, one explanation this study offers is that perceived stress scales account for life stressors that are not in direct relation to caregiving (e.g. physical symptoms of stress, finances, time commitments, and satisfaction/happiness). Another explanation that is offered is that caregivers feel more comfortable reporting stress when the question does not directly ask about stress in relation to their caregiving responsibilities. More specifically, caregivers may be hesitant to report they always or often feel burdened by their role, and therefore are more likely to report higher levels of stress unrelated to caregiving. It may be that caregivers do not see their role as burdensome. Other caregivers may be embarrassed or feel guilty if they report that their loved one causes them excessive worry and stress.

Limited research suggests there is an association between perceived stress and caregiver burden that indeed predicts caregivers' level of depression (Luchesia et al., 2016). However, to our knowledge, this was the first study to look at the relationship between these three variables in caregivers of HNC and LC. This study expanded the outcome variable to include anxiety as well as depression. Further, it used previous research on the relationship between caregiver burden and emotional distress, perceived stress and caregiver burden, and limited research on perceived stress and emotional distress to explore the independent and collaborative relationship among these two predictors and outcome variables. The findings of this study therefore add to the existent literature but also highlight the need for further exploration on variables like caregiver burden and perceived stress and how they directly and indirectly impact the experience of caregivers.

Implications for Research and Practice

This study has a couple implications for research and practice when working with HNC and LC caregivers. To begin, perceived stress as an independent variable is not often used in cancer caregiving research. As stated above, perceived stress as a predictor of emotional distress has typically been investigated among caregivers of older adults. Because the field supports the integrative relationship between stress and caregiver burden, specifically that caregiver burden involves stress, it may be possible that studies have not found the need to include both a caregiver burden measure and a perceived stress measure. This study suggests that it should be included as an independent predictor variable for psychological outcomes including depression and anxiety.

By including perceived stress as a predictor, studies will be able to account for more of the relationship between the experience of caregiving and potential negative psychological

outcomes such as distress. This study confirmed that there is a correlation between caregiver burden and perceived stress, but it is not too high of a correlation that the two scales are measuring the same construct. That is, there are contextual elements of stress outside of the caregiving role that are accounted for in their reported emotional distress. Therefore interventions and resources should be aimed at not only supporting caregivers in the “role” as a caregiver, but also work to address how additional life stressors could be impacting their experience caregiving (e.g. finances, work stressors, other relationships). Resources could also be provided to help reduce stress in the caregiver’s life so they are better equipped to deal with the excessive demands of caregiving.

The literature has identified some positive effects of the caregiving process that serve as a protective factor against the “burden” of caregiving. Often times, if the caregiver is able to recognize the positive aspects of their role (love, meaning, commitment), they have an increased sense of pride and self-worth as a caregiver (Nijboer et al., 1998). This study found that for some caregivers, their role as a caregiver and the stress they perceive in their life are not related. Those caregivers reported low levels of burden and high levels of stress. Visual inspection of the data in this study found this relationship to be true for some caregivers. Within this study, some caregivers reported very low levels of caregiver burden, but high levels of perceived stress. This suggests that further interventions should work to understand the caregiver’s subjective experience between caregiver burden and stress in their life. It would not be appropriate to work to improve the caregiver’s role if they do not see it as burdensome. It may instead be more important to provide resources and target alternative areas of stress in the caregiver’s life that is contributing to their levels of distress.

The implications for caregivers of HNC and LC include increased knowledge around their unique experience. This study has highlighted that these caregivers are particularly understudied and underrepresented in the caregiving literature (Precious et al., 2012). Because LC is the primary cause of cancer death among men and women in the United States and HNC accounts for approximately 300,000 deaths every year, there are a lot of caregivers for this population that are in need of emotional and tangible support. Therefore, this study adds to the literature on their unique experience and encourages further exploration as to how they can be better represented in the literature as well as brings attention to their psychosocial needs.

Limitations and Directions for Future Research

To our knowledge, this is the first study to look at the independent and collaborative relationship between caregiver burden, perceived stress, and emotional distress in HNC and LC caregivers. Findings from this study including, a positive relationship between perceived stress and caregiver burden and a positive relationship between caregiver burden and emotional distress yielded further support for the already known literature on cancer caregiving. These mentioned findings, in addition to a positive relationship between perceived stress and emotional distress as well as the collaborative effects of caregiver burden, perceived stress, and emotional distress do in fact add new information to the literature on caregiving for patients with HNC and LC.

As mentioned above, one observation that was made in regards to the data was that a number of caregivers reported low levels of caregiver burden but high levels of perceived stress. This would indicate that the caregiver is perceiving higher overall levels of stress in their life but not feeling burdened by their role as a primary caregiver. However, from this study it was discovered that there is a significant and positive relationship between caregiver burden and perceived stress for the majority of caregivers in the study. Therefore, future research may look

into why some caregivers perceive their role as burdensome and some do not as well as how caregivers separate stress related to caregiving and stress unrelated to the caregiving process.

Another limitation of this study is missing data. Caregivers systematically omitted certain variables of interest, reducing the sample size. More specifically, caregivers omitted information regarding the hours spent caregiving as well as income. One explanation for omitting hours spent caregiving may be that caregivers are unaware how many hours they spend providing care. Some individuals may not keep track, and others may be confused by what is considered “hours spent caregiving.” This may be especially true of spousal caregivers who live in the home with the cancer patient and spend the majority of their time together. An explanation as to why caregivers omit information regarding income is because it may be more sensitive in nature. Some individuals may not feel comfortable revealing their personal financial information.

TABLES

Table 1.
Study Demographic information

	<i>n</i>	<i>%</i>
Sex		
Female	106	76.2
Male	33	23.7
Language		
English	132	92.9
Spanish	10	.07
Insurance		
Medicaid	109	27.73
Medicare	178	45.29
VA	102	25.95
Private	4	1.02
Hours of Care		
Less than 5	20	15.5
5-10	19	14.8
10-20	12	9.2
More than 20	61	48.6

Table 2.
*Variable Means, Standard Deviations, Reliabilities,
 and Regression Correlations*

Variable	1	2	3	4	5
1. Perceived Stress					
2. Caregiver Burden	.43*				
3. Depression	.50*	.53*			
4. Anxiety	.59*	.65*	.77*		
5. Emotional Distress	.58*	.64*			
Mean	17.91	9.87	15.60	13.54	29.14
(SD)	(4.35)	(7.78)	(7.11)	(6.08)	(12.42)
Cronbach's α	.85	.88			.93

Note: * $p < 0.001$

Table 3. *Regression prediction of depression*

Variable	<i>B</i>	<i>SE(B)</i>	<i>t</i>	<i>p</i>
Gender	-.01	1.01	-.01	.99
Age	-.09	.03	-2.57	.01*
Language	1.78	1.69	1.05	.29
Insurance				
Uninsured*	-1.86	1.93	-.96	.33
Public	-2.09	1.20	-1.74	.09
Private	-2.20	1.43	-1.54	.13
Hours	-.10	.37	-.28	.78
ZBI	.36	.06	5.62	0**
PSS	.35	.11	3.21	.002*

Note: (N = 112). PSS = Perceived Stress Scale. ZBI= Zarit Burden Interview. R2 = .12 for control variables; R2 change = .36 when predictors are included. Total R2 = .48. Note: * p < .05, ** p < .01.

Table 4. *Regression prediction of anxiety*

Variable	<i>B</i>	<i>SE(B)</i>	<i>t</i>	<i>p</i>
Gender	-.01	.98	-.01	.99
Age	-.13	.03	-3.80	0**
Language	1.50	1.63	.92	.36
Insurance				
Uninsured*	-1.81	1.86	-.97	.33
Public	-2.36	1.16	-2.03	.04*
Private	-3.26	1.38	-2.36	.02*
Hours	.09	.35	.27	.79
ZBI	.45	.06	7.19	0**
PSS	.59	.11	5.52	0**

Note: (N = 112). PSS = Perceived Stress Scale. ZBI= Zarit Burden Interview. R2 = .17 for control variables; R2 change = .48 when predictors are included. Total R2 = .65. Note: * p < .05, ** p < .01.

Table 5. Hierarchical regression prediction of emotional distress (combined anxiety and depression)

Variable	<i>B</i>	<i>SE(B)</i>	<i>t</i>	<i>p</i>
Gender	.34	1.64	.21	.84
Age	-.20	.06	-3.48	.001**
Language	8.56	2.91	2.93	.004
Insurance				
Uninsured*	-.72	3.21	-.23	.82
Public	-4.80	1.95	-2.47	.02*
Private	-6.35	2.32	-2.74	.01*
Hours	-.25	.59	-.43	.67
ZBI	.72	.11	6.70	0**
PSS	1.01	.18	5.62	0**
PSS ²	.06	.03	1.99	.05*
ZBI*PSS	.09	.02	3.95	0**
ZBI*PSS ²	.00	.00	-.69	.49

Note: (N = 112). PSS = Perceived Stress Scale. ZBI= Zarit Burden Interview. R2 = .17 for control variables; R2 change = .47 when predictors are included; R2 change when interaction is included = .05. Total R2 = .68. Note: * p < .05, ** p < .001.

FIGURES

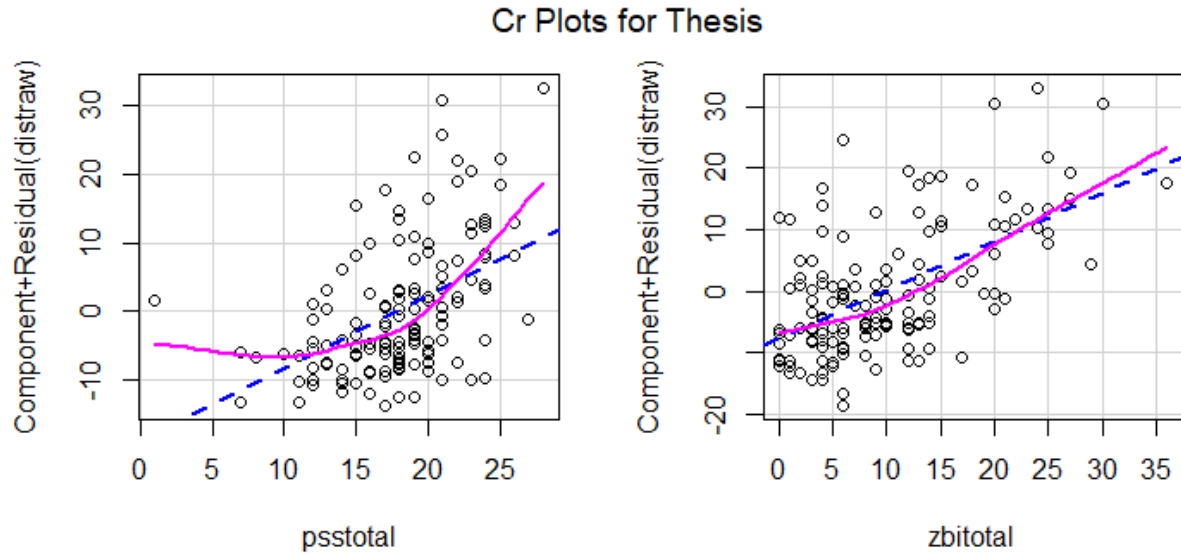


Figure 1. Scatter plot of the residuals for perceived stress and emotional distress and caregiver burden and emotional distress.

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