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# The Family Caregiver's Experience: Examining the Positive and Negative Aspects of Compassion Satisfaction and Compassion Fatigue Using a Stress Process Model

Susan Lynch

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**THE FAMILY CAREGIVER EXPERIENCE - EXAMINING  
THE POSITIVE AND NEGATIVE ASPECTS OF  
COMPASSION SATISFACTION AND COMPASSION  
FATIGUE USING A STRESS PROCESS MODEL**

by

**SUSAN H. LYNCH**

BSN, University of North Carolina Greensboro, 1989  
MSN, University of New Mexico, 1997

**DISSERTATION**

**Submitted in Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Philosophy  
Nursing**

**The University of New Mexico  
Albuquerque, New Mexico**

**May, 2015**

## **DEDICATION**

I would like to dedicate this Doctoral dissertation to my family. To my husband, George, who provided me unwavering encouragement, support, strength, and love through all the challenges faced in pursuit of my goals. To my children, Emily, Alissa, and Joshua who always had a smile, hug, or laugh when I needed one and understood my mental and physical absences at times during this process. To my sister, Karen, who throughout my life encouraged, listened and provided me the guidance needed when in doubt. Thanks to all of you for your individual and essential contributions to this work.

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**ABSTRACT**

Family caregivers significantly contribute to the provision of health care for their family members. This complex care can result in stress that may lead to both positive and negative consequences for the caregiver. Current literature tends to focus on negative consequences such as caregiver burden. Therefore, compassion fatigue and compassion satisfaction are proposed as concepts that may better reflect the family caregiving experience. Compassion fatigue is comprised of two components; burnout and secondary traumatic stress. The purpose of this study was to examine the concept of compassion fatigue and compassion satisfaction among family caregivers and to explore the relationship between caregiver burden and compassion fatigue to determine which characteristics were predictive for the level of compassion fatigue. Using a cross sectional descriptive survey design with a convenience sample, 168 family caregivers providing care for family members with chronic illness completed a web based survey. The survey included a demographic questionnaire, the Caregiver Burden Interview, the Professional Quality of Life measure and the Brief COPE inventory. Results from this

study revealed that the majority of participants reported a high level of caregiver burden, a moderate level of burnout, equal division of low and moderate levels of secondary traumatic stress, and a moderate level of compassion satisfaction. Analysis suggested that caregiver burden and compassion fatigue are similar, but distinct concepts and supported the use of compassion fatigue and compassion satisfaction as caregiving outcomes for family caregivers. Characteristics related to gender, caregiving demands, and caregiver resources resulted in differences found in compassion fatigue and compassion satisfaction scores with caregiver burden as the primary predictor that explained a substantial amount of variance in compassion fatigue scores.

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## **Chapter One: Introduction**

Family caregivers significantly contribute to the provision of health care for their family members. In 2009, approximately 65.7 million people in the United States served as informal caregivers (National Alliance for Caregiving & AARP, 2009). As increased health care costs prompt earlier transitions from acute care facilities to home, families will continue to serve a primary caregiving role for family members with chronic disease. Currently, family caregivers contribute a large portion of unpaid care for those with chronic disease. Nationally in 2009, it was estimated that family caregiving was valued at \$450 billion (Feinberg, Houser, & Chouta 2011).

In addition to the large volume of care provided by family members, the duration and intensity of caregiving duties are often unpredictable, creating stress that can result in the negative outcomes of caregiver burden and compassion fatigue. Although research exists regarding the burdens family caregivers face and interventions aimed at reducing those burdens, this research mainly accounts for the negative aspects of the caregiving experience. It is also recognized that the care family caregivers provide can result in positive outcomes, such as enhanced health, improved well-being, personal growth (Jones, Winslow, Lee, Burns, & Zhang, 2011) satisfaction, sense of fulfillment, and feeling good about caring (Greenwood, Mackenzie, Cloud, & Wilson, 2009). Therefore, current research is often polarized, focusing on either the positive or negative aspects of caregiving. To better understand the family caregiver experience and empower caregivers to continue to provide care to chronically ill individuals, it is necessary to examine both the positive and negative aspects of family caregiving to better represent the total caregiving experience.

Compassion fatigue is an alternative concept to caregiver burden that may better represent the family caregiver experience. Although compassion fatigue is similar to caregiver burden in that it represents the negative outcomes associated with caregiving, the concept is not viewed in isolation, but in relation with the positive outcomes that also result. According to Stamm (2010), the caregiving experience consists of both the concept of compassion fatigue that includes components of burnout and secondary traumatization and the positive outcome of compassion satisfaction (Stamm, 2010). Although the concept is most often associated with professionals, recently, the concept has been applied to family caregivers (Day & Anderson, 2011; Lynch & Lobo, 2012; McHolm, 2006; Perry, Dalton, & Edwards, 2010). Care provided by family members has become progressively more intensive and complex, demanding more from family caregivers. This changes the context of the caregiving experience. Therefore, parallels can be drawn between family caregiving and professional caregiving, such as nursing. Another important element to the caregiver experience is the long standing relationship between caregiver and care recipient. Caregiver burden is often conceptualized based on the impact the performed tasks have on caregiver, whereas, compassion fatigue is a concept in which the empathetic relationship between the caregiver and care recipient is foundational to resultant outcomes. In response, examination of the family caregiver experience from a different perspective is warranted to better understand the family caregivers' experience and direct future study.

### **Problem Statement**

A recent report (Feinberg et al., 2011) indicated that family caregivers provide a substantial amount of unpaid care for chronically ill family members. It is critical to the

health care system that family members continue to provide this care. Although caregiver burden among family caregivers is an important area of inquiry, it provides a perspective that is limited in scope due to its conceptual lack of clarity (Bastawrous, 2013) and its incomplete view of the experience by focusing on only negative outcomes. Compassion fatigue is an alternate concept to consider that may better characterize the total family caregiver experience. The concept embodies the empathetic foundation for which the caregiving relationship is derived and thus provides a kinder, gentler term to reflect the experience. Compassion fatigue has been studied in professional caregivers, including nurses, but the research on compassion fatigue in family caregivers is limited. Therefore, the examination of compassion fatigue in family caregivers and identification of factors that influence risk can provide additional insight into the family caregiver experience and provide the foundation for future interventions.

### **Purpose of the Study**

The purpose of this study was to examine the concept of compassion fatigue among family caregivers using a cross-sectional descriptive survey design with a convenience sample. A second purpose was to explore the relationship between caregiver burden and compassion fatigue and to determine which characteristics were predictive for the level of compassion fatigue in primary family caregivers for care recipients with chronic disease.

### **Research Questions**

The specific aims of the study were to examine the positive (compassion satisfaction) and negative (compassion fatigue) outcomes of caregiving in family caregivers and identify factors— including caregiver burden, social support, coping,

length of time caregiving, caregiving demands, and background context—that contributed to the level of compassion fatigue.

The following five research questions guided the study:

1. What is the level of compassion fatigue and compassion satisfaction in family caregivers?
2. What is the relationship between caregiver burden and compassion fatigue?
3. Do background context factors (age, gender, ethnicity, employment status, caregiver education, caregiver relationship, income) contribute to differences in compassion fatigue scores?
4. Do caregiving demands, length of time caregiving, social support, coping, and caregiver burden contribute to the prediction of compassion fatigue in family caregivers?
5. Do caregiving demands, length of time caregiving, social support, coping and caregiver burden contribute to compassion satisfaction in family caregivers?

### **Significance of the Study**

#### **Role of Family Caregivers**

The definition of family caregiver varies among research studies; however, one criterion generally acknowledged is that the care provided is unpaid. Therefore, often the term “informal caregiver” is used synonymously with “family caregiver” (Bastawrous, 2013). Family caregivers are often defined by the care they provide, including the tasks they perform and the extent or time required performing this care (Family Caregiver Alliance, 2006).

Family caregiver roles may vary in number and scope. They may include providing companionship and emotional support, completing household chores, handling financial matters, providing transportation, accompanying the recipient to medical appointments, providing personal care such as bathing and dressing, taking responsibility for nursing procedures and medication administration, and serving as the patient advocate and care coordinator (Feinberg et al., 2011). Family caregiving positively impacts the health outcomes of care recipients and allows them to live independently longer thus reducing readmissions and delaying or preventing nursing home placement (Institute of Medicine, 2008). Although these duties produce positive outcomes for the care recipient, caregiver, and health system, they can also result in some negative outcomes for the family caregiver.

### **Difficulties Faced by Family Caregivers**

In addition to large numbers of people in the United States who serve as caregivers, 80% of the people who require care at home depend solely on family and friends, with the amount of care needed averaging 20-25 hours per week (Institute of Medicine, 2008). Most family caregivers are not prepared for this role and are often at risk for health problems themselves (Family Caregiver Alliance, 2006). This places a tremendous physical and economic burden on family caregivers. Over 30% experienced high rates of burden and stress due to the large amount of care they provided (National Alliance for Caregiving & AARP, 2009).

As families continue to serve as an important resource for those with chronic disease, the caregiving role can place the family caregiver in a vulnerable position. Providing care to a chronically ill care recipient can result in negative effects such as



deteriorating physical and psychological health, social isolation, and decreased quality of life (Feinberg et al., 2011). Feinberg et al. (2011) reported that 17-35% of family caregivers viewed their health as fair to poor and 52% reported caregiving taking them away from friends or family. The Family Caregiver Alliance (2006) reported that family caregivers are at risk for higher rates of depression, high levels of stress and frustration, worse health, increased risk of heart disease, lower levels of self-care, and increased mortality when compared to noncaregivers. In addition, caregivers may have to assume some of the cost of caregiving themselves.

### **Positive Outcomes**

Although caregiver research focuses primarily on the negative consequences of caregiving for the family caregiver, it is recognized that positive outcomes also exist for family caregivers. In a recent study, Jones et al. (2011) developed the Caregiver Empowerment Model, based partly on Pearlin's stress model, to recognize and predict the positive outcomes of caregiving for the family caregiver so that interventions can be developed to guide practice. The positive outcomes included enhanced perceived physical and mental health, personal growth, and existential well-being (Jones et al., 2011). Supporting this model, Morrison (1999) found that reported positive aspects of caregiving included a sense of fulfillment and improved relationships. These findings are further supported in a systematic review of qualitative research aimed at outcomes for carers of stroke survivors. Positive outcomes were identified in seven of the 17 studies reviewed. Those outcomes included feeling pride and satisfaction, sense of fulfillment, feeling good, and perceived closer relationship (Greenwood et al., 2009). Morrison (1999) reported that studies supported the view that the caregivers' appraisal of stressors

and availability of resources buffered the effects of the stressors, and later suggested that positive consequences of caregiving could do the same, making a connection between appraisal and positive outcomes. Jones et al. (2011), in their review of the literature, supported this conclusion. Positive outcomes, therefore, can protect against negative outcomes. In response, this study aims to examine compassion fatigue in the context of the caregiving experience to examine both positive and negative consequences so that future interventions can be developed to support family caregiving.

### **Current Research**

**Caregiver burden.** Family caregivers experience stress as the demands and roles change in the caregiving relationship. As the stress of caregiving accumulates, caregiver burden occurs. O'Rourke and Tuokko (2004), in a study of caregiver burden and depression, state that “burden is seen to result when a subjective determination is made that current and future resources are insufficient to contend with role demands” (p. 49). In a concept analysis, Chou (2000) defined caregiver burden as “an individual’s subjective perception of overload in one or more of four perspectives: physical, psychological, social, and financial through the caregiving process” (p. 405).

Caregiver burden is a concept used best to reflect the degree of caregiver stress. It is subjectively determined by the family member and is conceptually unclear as to its usefulness as an outcome to measure the impact on the caregiver or the care being provided (Bastawrous, 2013). In addition, Greenwood et al. (2009) noted that in the qualitative family caregiving studies reviewed, the term *burden* was minimally used by caregivers to describe the family caregiving experience. The authors proposed that the term may be too “non specific to be relevant” or that “carers may not perceive their role

as burdensome” (p. 349). As caregiver burden reflects the negative consequences of caregiving, the concept is limited and thus may not reflect accurately the total caregiving experience (Bastawrous, 2013).

**Compassion fatigue.** As an alternative, compassion fatigue is a concept that is often discussed in relation to professional caregivers. However, it has been suggested that compassion fatigue is relevant to family caregivers as well (Day & Anderson, 2011; Lynch & Lobo, 2012; McHolm, 2006; Perry et al., 2010). Figley (1995) defined compassion fatigue “as a state of exhaustion and dysfunction—biologically, psychologically, and socially—as a result of prolonged exposure to compassion stress and all that it evokes” (p. 253). Lynch and Lobo (2012) added that “compassion fatigue occurs when a caregiving relationship founded on empathy potentially results in a deep psychological response to stress that ultimately progresses to physical, psychological, spiritual, and social exhaustion” (p. 2128). Therefore, the psychological response to the empathy expressed and suffering experienced is foundational to the continued progression of stress and resulting compassion fatigue. Compassion fatigue represents the negative consequences of caring and consists of two parts; burnout and secondary traumatic stress. It characterizes the dysfunction that results; compassion satisfaction, on the other hand, reflects the positive aspects of caregiving. Therefore, compassion satisfaction in addition to compassion fatigue, are recognized as major outcomes of caregiving (Stamm, 2010).

Literature regarding compassion fatigue in family caregivers is limited to four published sources. To date, no quantitative studies have been found. However, recent reviews and research are beginning to explore the presence of compassion fatigue in

family caregivers. Findings indicated that the role of empathy and over-identification with caring are foundational to the development of compassion fatigue in family caregivers (Perry et al., 2010; Ward-Griffin, St-Amant, & Brown, 2011). Although both compassion fatigue and caregiver burden are viewed as negative consequences of caregiving stress, it is unclear if the two are distinctly different concepts. It is proposed in this study that compassion fatigue is an alternative concept that may better represent the outcomes of family caregiving. Therefore, examination of compassion fatigue is needed to explore its relationship to caregiver burden and to demographic characteristics to determine how it impacts the family caregiver. The study results can provide additional insight into family caregivers' experience so that interventions can be developed to promote positive outcomes and prevent negative ones.

### **Public Policy**

The study of family caregiving is not only important for the caregiver and care recipient, but has major implications for the healthcare system and public policy. Historically, family caregiving has been viewed by Americans as an expected role. As a result, policymakers have not considered it a significant policy problem. The Institute of Medicine report (2008) stated that "the motivation for providing this type of assistance is, most commonly, emotional commitment and personal relationship. Public policy has traditionally viewed informal caregivers' service as a personal, moral obligation, and not as an extension of the workforce" (p. 247).

However, societal and healthcare system changes have occurred that warrant addressing family caregiving issues. Several key changes magnify this issue including, an aging population resulting in more elderly requiring care; more women in the paid

workforce, thus reducing the availability of family caregivers; advanced technology in home health care, increasing the need for training; and nontraditional families finding it difficult to provide care due to legal and healthcare system policies (Levine, Halper, Peist, & Gould, 2010). Family caregivers are irreplaceable. As families continue to significantly contribute to the provision of care for ill family members, the often resultant negative outcomes of family caregiving will increase, resulting in the recognition that family caregiving is a public concern (Feinberg et al., 2011).

### **Nursing Impact**

Compassion fatigue is an area of research with nursing implications. As chronically ill persons are transitioned home to the care of their families, nurses must be aware of the potential negative consequences that result from compassion fatigue. Nurses provide an essential role in the provision of care for chronically ill adults; however, nurses must also be aware of and recognize the potential negative consequences for family caregivers that can result from providing intensive, high quality care. Family members must remain healthy and have support so that they can continue to provide care to their loved ones. Support has been identified as one strategy to treat and prevent compassion fatigue (Figley, 2002).

Recognition of compassion fatigue is important for prevention and treatment. Nurses may be in a better position to recognize the signs of compassion fatigue as they may have observed it in themselves or others. As members of the healthcare team, nurses are positioned to be leaders in the efforts to provide services not only to the care recipient but to the family caregiver.

## Theoretical Framework

### Stress Process Model

The Stress Process Model examines the development of negative outcomes from primary subjective and objective stressors plus secondary stressors. The objective and subjective measures specifically address the physical and emotional stressors that accompany caregiving. Mediators, including support and the caregiving context, can impact this process and resultant outcomes (Gaugler, Anderson, Zarit, & Pearlin, 2004). An important element in this model is the focus on the *process* of stress, examining the relationships among concepts that vary and change over time. The model examines four domains of the stress process: background and context of stress, the stressors, the mediators of stress, and the outcomes and manifestations of stress (Pearlin, Mullan, Semple, & Skaff, 1990).

In application to family caregivers, Pearlin et al. (1990) stated that the background and context of the stress for caregivers included individual caregiver characteristics such as age, gender, ethnicity, educational, occupational, and economic characteristics. Additional components important to the caregiver context include caregiving history, family and network composition, and access to and use of resources. The stressors are conceptualized as those “conditions, experiences, and activities that are problematic for people; that is, that threatened them, thwart their efforts, fatigue them, and defeat their dreams” (Pearlin et al., 1990, p. 586). Stressors are divided into primary and secondary stressors which are interrelated. Caregiving is conceptualized as the primary stressor recognizing that other stressors related to life and daily hassles will play a secondary role.

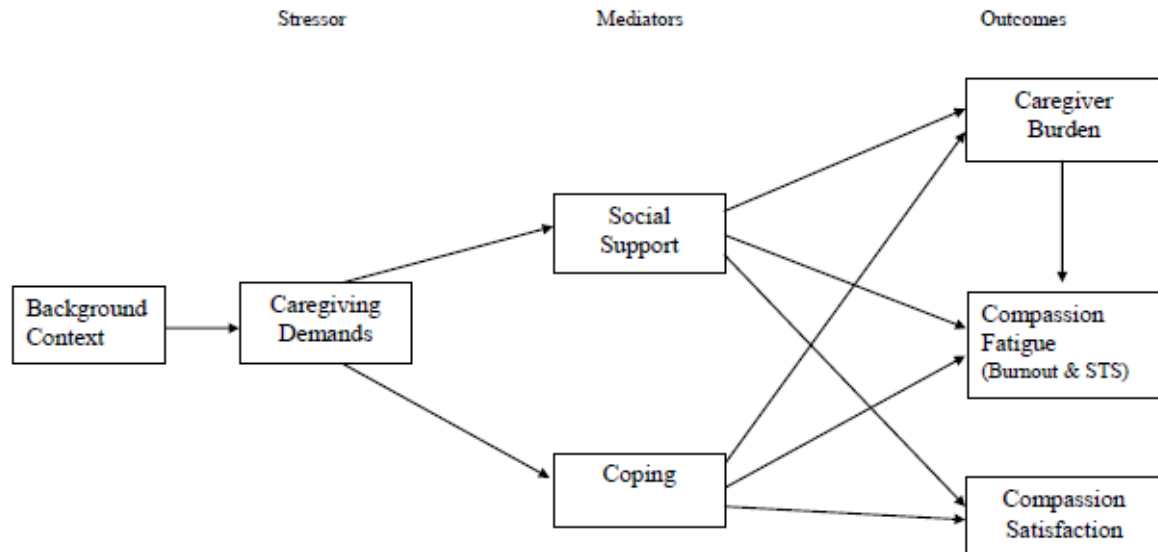
Effective coping and social support are viewed as mediators. Interest in these mediators is based on trying to determine if differences in how one responds can be attributed to coping mechanisms or social support (Pearlin et al., 1990). Pearlin, Lieberman, Menaghan, and Mullan (1981) referred to coping in relation to its function, which includes “the modification of the situations giving rise to stressful problems; the modification of the meaning of problems in a manner that reduces their threat; and the management of stress symptoms” (p. 341). Additionally, Pearlin and Skaff (1996) perceived coping behaviors as evolving over time and focused on the meaning of the situation rather than managing or changing it. Similarly, Patterson and Garwick (1998) deemed coping as adaptive, using cognitive and behavioral strategies to alter the meaning of the situation as a way to reduce and/or manage their demands.

Social support is a concept not clearly defined in the literature. Pearlin et al. (1981) noted that the presence of social support is dependent on the depth of relationship and frequency of interaction between individuals and, further, that being part of a social network does not necessarily equate to social support (Pearlin et al., 1981). However, social support is reported to be a buffer to stressors by preventing or inhibiting the development of secondary stressors (Pearlin et al., 1990).

Finally, as Pearlin et al. (1990) pointed out, outcomes are based on how the stressor affects the caregiver and are focused on well-being, physical and mental health, and the ability of caregivers to sustain themselves in their roles. The authors also suggested that the different outcomes in response to stressful situations are not necessarily interchangeable but need to be viewed as interrelated.

This study aimed to examine the relationships of the concept model (Fig. 1) as depicted according to Pearlin's stress process model. No studies were found that compared the concepts of caregiver burden and compassion fatigue. Therefore, this exploratory study provided descriptive data to determine the level of compassion fatigue and compassion satisfaction in family caregivers, the relationships between outcomes of caregiver burden, compassion fatigue, and compassion satisfaction, and what factors contribute to the level of compassion fatigue.

Figure 1: Concept Model



Adapted from Pearlin's Stress Process Model

### Assumptions

The study had the following assumptions:

1. A personal relationship exists between the family caregiver and care recipient.



2. Family caregivers express empathy toward the care recipient.
3. Family caregivers experience stress.
4. Family caregiving results in positive and negative outcomes which impact the family caregiver, care recipient, and the entire family.

### **Limitations**

The study had the following limitations:

1. The cross-sectional design examines family caregivers at one point in time that may not accurately reflect the positive and/or negatives outcomes under study.
2. The sample is limited to family caregivers in one southern state. This specific geographic area may limit the generalizability of the results.
3. Variables not examined in this study may impact the results. They may include feelings of obligation, past poor relationship with the care recipient, and unreported psychological problems such as depression.

### **Definition of Terms**

#### **Family caregiver**

**Theoretical definition:** “A caregiver is an unpaid individual (a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks” (Family Caregiver Alliance, 2012).

**Operational definition:** A family caregiver is one who self-identifies as a primary family caregiver.

**Care recipient**

**Theoretical definition:** The individual for whom the family caregiver provides service, including activities of daily living (ADLs), instructional activities of daily living (IADLs) or both.

**Operational definition:** The individual the family caregiver identifies as the care recipient.

**Stressor**

**Theoretical definition:** Life events and strains experienced by an individual that result in disequilibrium (Pearlin et al., 1981).

**Operational definition:** Caregiving is the primary stressor experienced by the family caregiver.

**Caregiving demands**

**Theoretical definition:** The services provided, including activities of daily living (ADLs), instrumental activities of daily living (IADLs), and/or complex clinical tasks.

**Operational definition:** Caregiving demands are measured by participants' selection of the associated ADLs, IADLs and/or complex clinical tasks for which they assist the caregiver recipient.

**Compassion fatigue**

**Theoretical definition:** In family caregivers, "compassion fatigue occurs when a caregiving relationship founded on empathy potentially results in a deep psychological response to stress that ultimately progresses to physical, psychological, spiritual, and social exhaustion" (Lynch & Lobo, 2012, p. 2128).

**Operational definition:** Compassion fatigue is measured by the Professional Quality of Life Scale (ProQOL) (Stamm, 2010).

### **Caregiver burden**

**Theoretical definition:** “An individual’s subjective perception of overload in one or more of four perspectives: physical, psychological, social, and financial through the caregiving process” (Chou, 2000, p. 405)

**Operational definition:** Caregiver burden is measured by the Zarit Burden Interview (ZBI) (Zarit, 1983).

### **Social support**

**Theoretical definition:** Social support is defined as “the access to and use of individuals, groups, or organizations, in dealing with life’s vicissitudes” (Pearlin et al., 1981, p. 340).

**Operational definition:** Social support is measured by the Brief COPE inventory subscales of use of instrumental social support and use of emotional support (Carver, 1997).

### **Coping**

**Theoretical definition:** Coping is defined as the “behaviors and practices of individuals as they act on their own behalf” as they refer to the management of situations, meaning, and symptoms (Pearlin et al., 1998).

**Operational definition:** Coping is measured using the Brief COPE inventory (Carver, 1997).

## **Chapter Two: Literature Review**

The major purpose of this literature review is to examine theoretical frameworks used in the family caregiving literature and to examine the individual study concepts of caregiving demands, social support, coping, caregiver burden, compassion fatigue, and compassion satisfaction. To study family caregivers, a review of the major theoretical frameworks used in research provides the foundation needed to guide this study and examine its related concepts. Furthermore, as the theoretical framework informs the development of a conceptual model, a review of the major concepts provides an understanding of the proposed relationships and subsequent research questions.

### **Theoretical Frameworks**

In studies of family caregiving, researchers use many theoretical approaches. They include but are not limited to precarious ordering, family resiliency model, role theory, trajectory framework, transitions theory, and the stress process model. A review of the major theoretical approaches provides support for the decision to use the stress process model in this study.

### **Precarious Ordering**

Precarious ordering addresses the phenomenon of family caregiving over a lifetime. When faced with multiple competing demands of caring, caregivers experience a two-stage process. First, they move from a reactive stage of dissonance to a proactive stage of relative order within their environment. Multiple demands result in fraying connections that include the challenges of daily struggles, altered prospects, and ambivalent feelings. Precarious ordering occurs when caregivers create order out of these fraying connections by setting boundaries, negotiating, and repatterning care.

Additionally, the theory acknowledges the positive and negative outcomes that occur as a result of the demands of caring placed on families within their environment (Wuest, 2001).

The theory developed from qualitative studies using grounded theory that involved children with chronic otitis media and caregivers of family members with Alzheimer's disease. The theme "obligation of care" emerged, which shifted the focus of inquiry to a feminist lens exploring caring and caregiving of women who had poor past relationships with the ones for whom they provided care (Wuest, 2001; Wuest & Hodgins, 2011).

One of the major strengths of the theory is the acknowledgement of women's predominant role in family caring. While a strength, this is also a limitation in its application as it is unclear if the theory would be supported with male caregivers. For the theory to be useful in all populations, men's role in caregiving must be acknowledged. It was estimated that 34% of caregivers were men and this number was expected to rise. This figure represents the significant contribution of men to family caregiving (National Caregiver Alliance & AARP, 2009). Gender differences in caregiving continue to be an area in need of further research. Another strength of the theory is its recognition of both positive and negative outcomes in caregiving. Wuest (2001) recognized that caregiving literature focused solely on either the positive or the negative aspects of caregiving, and felt that these perspectives did not capture the complexity of the caring experience. Therefore, through qualitative inquiry, elements of both the negative aspects of fraying connections and the contribution of caring rewards through the process of precarious

ordering emerged as major constructs for the theory, which were later validated with quantitative results (Wuest & Hodgins, 2011).

Although the theory was developed using multiple diverse groups over time, the research conducted contained a relatively small specific sample. It is unclear whether the identified specific diverse groups of caregivers of children with chronic otitis media, Alzheimer's family members, and abused caregivers are representative of caregivers in general. Additionally, retrospective analysis of previously collected data through a feminist lens provided a comparison for data extraction, but remains limited in scope. Questions remain as to whether other themes and gaps would have arisen if the feminist lens had been initially applied to the previous studies.

Finally, overall application of the theory in healthcare literature is limited. No studies were found in current nursing, social work, or family literature that utilized the theory in research with the exception of Wuest (Wuest, 1997a; 1997b; 2000a; 2000b; 2001; Wuest & Hodgins, 2011). However, references to Wuest's work is cited in other family caregiving articles (Clemmer, Ward-Griffin, & Forbes, 2008; Forssen & Carlstedt, 2008). This lack of utilization as well as the primary focus of precarious ordering on women needs to be considered prior to use in future caregiving research.

### **Resiliency Model**

The resiliency model of family stress, adjustment, and adaptation was developed from the culmination of research on family stress. Often referred to as the family resiliency model, it emerged as an extension of previous stress models in an effort to address the added elements of family functioning and family resiliency within ethnically and structurally diverse families. The model's intent was to explain why among families

that experience similar situations, some are able to overcome crises and others are not. The model examines particular characteristics, relationships, and processes within the family and community that promote family adaptation to crises (McCubbin, Thompson, & McCubbin, 1996).

The family resiliency model consists of two major phases: adjustment and adaptation. During the adjustment phase, families attempt to maintain the established patterns of family functioning to handle daily activities in response to family stressors. If the family adjusts, bonadjustment occurs. This refers to the families' ability to handle the stressors by utilizing their established patterns of functioning, appraisal, resources and problem solving to maintain balance and harmony. If the stressor continues and intensifies, and the family is unable to effectively adjust, maladjustment occurs (McCubbin et al., 1996).

Progression to the adaptation phase is initiated by the family's inability to use established patterns of functioning effectively to reestablish harmony and balance in response to the crisis. Patterns of functioning, internal family resources, network of social support, the family's situational appraisal and situational processes, added to the family's problem-solving and coping mechanisms, interact over time to introduce changes directed to restoring balance to achieve bonadaptation. The process is cyclical, in that if efforts do not prove successful, maladaptation occurs and the adaptation phase starts over (Greeff & Wentworth, 2009; Kosciulek, McCubbin, & McCubbin, 1993; McCubbin et al., 1996).

The model seeks to examine common elements in the family's stress response while understanding the family's unique personal perspective (Walsh, 2003). In

examining stressors, focus is on the strengths of the family in an effort to support, sustain, and generate strategies to foster adaptation and create opportunities for family growth that can be utilized in future challenges (Black & Lobo, 2008; Hamilton & McCubbin, 1988). Resilience occurs at multiple levels including the individual, family and community. Each level is unique but related. A change in one affects the others (Hawley, 2000; Kosciulek et al., 1993; McCubbin et al., 1996).

The model offers a framework to study families in crisis and was specifically used in family caregiving research involving family members with chronic disease or trauma (Frain et al., 2007; Greeff & Wentworth, 2009; Kosciulek et al., 1993; White, Richter, Koeckeritz, Lee, & Munch, 2002). One of the major strengths of using the model in family caregiving research is the focus on the family and their strengths. Even though the individual caregiver is an important element, the caregiving relationship involves more than one caregiver, thus it is critical to acknowledge family dynamics and processes. Therefore, the resiliency model provides a framework to study caregiving from both an individual and family perspective (Frain et al., 2007). The complexity of family research, however, raises questions regarding data collection and analysis. Family unit analysis is difficult to obtain in that data are collected by individual or multiple family members and processed to represent the family. Thus, it is unclear whether individual assessment is reflective of family processes (De Haan, Hawley, & Deal, 2002). In addition, even though the resiliency model focuses on family strengths and processes related to adaptation during crisis and is applicable to caregiving research, resiliency concept measurement associated with the model may not provide a complete view of the caregiving experience. Therefore, additional concepts and measurement instruments need



to be considered to address research questions regarding specific family caregiving outcomes. For the purposes of this study, the resiliency model may be best used to direct future study aimed toward families, not individuals.

### **Caregiving Trajectory**

The idea of trajectory arose from chronic illness and end-of-life research as it addresses the complexities of living with chronic illness over time. The concept has been applied to various chronic illnesses and now is applied specifically to caregiving (Penrod, Hupcey, Baney, & Loeb, 2011). The end-of-life caregiving trajectory was developed by Penrod et al. (2011) from a grounded theory study of informal caregivers. The application of the framework focused on informal caregiving through the end of life. The authors described phases of trajectory that centered on the major theme of seeking normal in response to changing demands. The four phases are sensing a disruption, challenging normal, building a new normal, and reinventing normal. *Sensing a disruption* is initiated when the caregiver and/or care recipient notice a health problem and a subsequent diagnosis is made. This is an abrupt transition which leads to the second phase, *challenging normal*. This phase is characterized by managing care with new treatments and medical appointments led by the experts. The caregiver attempts to maintain a balance between the medical care required and a normal life. Transition to *building a new normal* occurs when the caregiver acknowledges the prognosis of end of life and there is nothing more to be done. Caregivers take an active role in caregiving as they establish patterns to manage care 24 hours a day. As the recipient approaches end of life and death occurs, the established patterns are disrupted and the caregiver enters the final trajectory,

*reinventing normal*. This phase is characterized by grieving and developing a new normal without the care recipient (Penrod et al., 2011).

Individuals experience variations of all trajectory phases. The death trajectory, whether expected, mixed, or unexpected, influences the duration and progression through each phase. Therefore, the anticipation of death, not the disease, is the key factor in the caregiving trajectory (Penrod et al., 2011). Although the concept of trajectory is not new, its application to caregivers is unique. However, as this model addresses caregiving through the end of life, it is unclear whether the model would describe the experiences of caregivers where end of life is not imminent or anticipated. Ersek (2011) added that illness trajectory is one factor that may be too simplistic to address the complexities of caregiving. Other factors such as role strains, finances, and social support are not addressed in the end-of-life caregiving trajectory as they are in the stress process model (Ersek, 2011). Finally, this new model is untested as it has not been used as a theoretical approach in research to date.

### **Transitions**

The theory of experiencing transitions is a mid-range nursing theory that addresses changes and demands placed on clients and families as they anticipate transitions. The theory identifies three types of transitions: illness transitions, developmental and lifespan transitions, and social and cultural transitions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Family caregiving is viewed by Meleis et al. (2000) as an example of social and cultural transition. The theory was informed by multiple grounded theories. For example, one study explored role acquisition patterns for family caregivers of cancer clients receiving chemotherapy. Findings revealed central

theme of shifting patterns of self-care and caregiving that characterized the family caregiving experience for the dyads studied. As the theory was developed, multidimensional and complex transitions were described by the types, patterns, and properties observed. In addition to the characteristics that described the transitions, it was noted that personal and environmental factors facilitated or hindered transitions. As a result, patterns of response, including process indicators and outcome indicators, were identified. Process indicators of healthy transitions included feeling connected, interacting, being situated and located, and developing confidence and coping. Outcome indicators included mastery and fluid integrative identities (Meleis et al., 2000). Therefore, transitions occurred as a response to change and are viewed as both a process and outcome (Blum & Sherman, 2010).

In family caregiving, transitions in the care recipient's illness phases and the caregivers' response and adaptation to the caregiving role are important. Blum and Sherman (2010) reported that caregiving literature has focused on the illness process of the care recipient with no studies addressing family caregiver transitions. However, the authors viewed the theory of experiencing transitions as a potential framework to use in caregiving research (Blum & Sherman, 2010). Transitions are noted as a process and an outcome; therefore, the theory can be used by health professionals to help guide the client and family caregiver through transitions (Blum & Sherman, 2010). Although the concept of caregiving transitions is cited in the literature (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Lawton, Moss, Hoffman, & Perkinson, 2000; Seltzer & Li, 2000), the theory of experiencing transitions has not been applied extensively in family caregiving research. One reason may be the focus on the care recipients' disease process, which only

informs part of the caregiving experience. In the family caregiving study cited by Meleis et al. (2000) they identified four major periods: the diagnostic period, the side-effect-intensive period of chemotherapy cycles, the junctures between treatment modalities, and the completion of treatment. These identified periods highlight the focus on disease and treatment and may not be reflective of the entire caregiving experience. Therefore, based on its specificity, focus on disease process, and its limited use in research, the relevance of this study is questionable.

### **Role Theory**

Role theory arose from sociology and social psychology with differing perspectives from multiple role theorists. Various versions of role theory exist including functional, symbolic interactionist, structural, organizational and cognitive role theories (Biddle, 1986). Lynch (2007) discussed various views of role theory from functionalist, interactionist and cognitive perspectives. Whereas, Collier and Callero (2005) linked the traditional structural and interactionist perspectives of role theory to the psychological perspective of social cognition, identifying role as a resource.

Goode (1960) introduced the theory of role strain as a normative process where individuals have multiple role relationships and cannot fully satisfy all role demands placed on them, a situation that results in role conflict. In response, individuals seek ways to balance the roles through role decisions and bargains (Goode, 1960). Dautzenberg, Diederiks, Philipsen, and Tan (1999) further explained that the involvement in multiple roles leads to role strain and distress and that the goal is to manage the demands to acceptable limits. Strategies used to manage roles include bargaining, delegating, compartmentalizing, and acquiring new roles (Dautzenberg et al., 1999).

A major premise of the theory is that societal structures are made up of role relationships (Goode, 1960). Biddle (1986) further explained that “human beings behave in ways that are different and predictable depending on their respective social identities and the situation” (p. 59). In application to family caregiving, Lee (2007) explained that expectations influence individual behaviors. As a result, obligations to assume family caregiving roles occur. Family is viewed by Goode (1960) as the center of role allocation and is pivotal in decreasing role strains and maintaining balance. However, in maintaining balance it is acknowledged that family roles are difficult to eliminate (Goode, 1960). Schumacher (1995) focused on caregiver role acquisition and argued that elements of structural and interactionist role theory are used in combination to create situated interaction. Situated interaction is a process where role partner interaction and the social environment influence the caregiving experience. Although Schumacher (1995) discussed the idea of role-making and one’s transition to the caregiving role, she noted that longitudinal studies are needed to examine role transitions over time.

Caregiving roles have emerged as an area of interest in the caregiving literature. Specifically, examining women caregivers and role conflicts has attracted the interest of researchers as more women have entered the work force (Dautzenberg et al., 1999; Lee, 2007). Therefore, role theory, in particular role conflict and role overload, are concepts important in gendered aspects of caregiving (Bastawrous, 2013). In addition, role acquisition as described by Schumacher (1995) examined the transition to the role of caregiver, which is an important area of inquiry to address early issues faced by caregivers. However, it is unknown whether the theory is adequate to examine the multiple transitions that occur in a caregiver’s experience, including the positive and

negative outcomes of the caregiving experience. Finally, Biddle (1986) referenced theoretical limitations in role theory that included concept confusion and changing assumptions under different circumstances evident by its references to theater and the use of roles. Additionally, the focus of the theory has been on alternate views such as role conflict, role taking, and role playing instead of role origins, effects, expectations and social positions. Therefore, the application of role theory is limited in scope for the purposes of this study.

### **Stress as a Process**

Two major stress models that describe stress as a process include the transactional model of stress and coping by Lazarus (1990) and the stress process model by Pearlin (Pearlin, 1989; Pearlin, Lieberman, Menaghan, & Mullan, 1981). Differences between these two perspectives are rooted in their disciplinary focus: psychological stress versus sociological stress. Psychological stress is based on individuals' appraisal of stress exceeding their resources within their environment. This appraisal can be seen as either a threat of harm or harm, or an optimistic, positive attitude in response to the stressor (Lazarus, 1990). In Pearlin's view, social structures and context are integral to stress process. As such, it is not the mere event that causes stress, but the context in which an individual experiences the event. Therefore, the sociological view of stress is interested in patterns and regularities that are shared by individuals who experience stress (Pearlin, 1989). Family caregivers share in a similar situational context and role that contributes to the experience of stress. In addition, both Lazarus and Pearlin view coping as a mediator (Folkman & Lazarus, 1988; Pearlin et al., 1981); however, Pearlin et al. (1981) also see social support as a mediator, whereas Lazarus (1990) views social support as an

environmental variable acting as a causal antecedent in the process. Whether one chooses a psychological or sociological approach to examine stress, Pearlin, Mullan, Semple, and Skaff (1990) specifically applied the model to family caregiver experiences, and it has subsequently been used in multiple studies examining the family caregiving experience. (Bainbridge, Krueger, Lohfeld, & Brazil, 2009; Bolden & Wicks, 2010; Cain & Wicks, 2000; J. Chronister & Chan, 2006; Fletcher, Miaskowski, Given, & Schumacher, 2012; Gaugler, Anderson, Zarit, & Pearlin, 2004; Kim, Chang, Rose, & Kim, 2012; Pearlin et al., 1990; Son et al., 2007). Therefore, based on its sociological view of stress, wide range of application, and specificity to family caregivers, Pearlin's stress process model best provides the theoretical foundation for this study.

### **The Stress Process Model**

The stress process is described by Pearlin et al. (1981) as a function of three conceptual domains: sources of stress, mediators of stress, and manifestations of stress. In a longitudinal study of the stress process, major sources of stress identified included eventful experiences and chronic strains. The interrelationship between these two sources results in stress. In addition, instances in which self-concept is altered contributes to the development of stress. However, it is recognized that the intensity of stress and its impact are not the only elements to consider. In addition to these elements, how people respond to stress can mediate or alter the impact of the stress on them. Pearlin et al. (1981) identified two mediators: coping and social support. As a result of these processes, Pearlin et al. observed manifestations or outcomes of stress. In applying the stress process to caregiving, Pearlin et al. (1990) described the following concepts of background and context of the stress process, primary and secondary stressors, mediators, and outcomes.

**Background context.** The stress process is influenced by key characteristics of the caregiver and care recipient. These characteristics represent the various differences among individuals that determine how they are located within social systems. Characteristics identified include age, gender, ethnicity, education, occupation, and economic status. These characteristics can influence the intensity of stressors, the resources available to manage stressors, and the ways in which the stress is expressed—all of which impact the stress process. Additional factors that influence the stress process include the caregiving history and access and use of resources, including family network and community programs (Pearlin et al., 1990).

Although criticized as inadequate by Penrod et al. (2011) for subsuming the concept of trajectory under the broad conceptualization of background context in the stress model, this approach takes into account the multiple and various factors that can impact an individual caregiving experience, and thus it can better address the individual aspects in the caregiving relationship. Bastawrous (2013) agreed that illness context related to trajectory is an important element to consider, one which the stress process model addressed.

In addition to trajectory, role acquisition and transitions are deemed important to the caregiving experience, according to Gaugler, Zarit, and Pearlin (2003). In a study of caregiving onset and role transition, the authors acknowledged that background characteristics, caregiving demands, and emotional support influence the caregiving experience and thus included them as covariates in the study. Considering these characteristics, it was found that those who transitioned abruptly to the caregiving role were less able to adapt to it, resulting in more distress, and that they were more likely to



relinquish the caregiving role, leading to increased institutionalization. Likewise, those who acquired the role demands more gradually experienced less distress (Gaugler et al., 2003).

**Primary stressors.** Stress arises from experiences. Experiences that interest stress researchers often are categorized as life events or chronic strains (Pearlin, 1989).

Stressors are conceptualized by Pearlin et al. (1990) as “conditions, experiences, and activities that are problematic for people; that is, that threaten them, thwart their efforts, fatigue them, and defeat their dreams” (p. 586). In the stress process model, stressors are categorized as primary and secondary. Primary stressors are the conditions that drive the stress model, such as caregiving demands; they are classified as objective and subjective indicators. Objective indicators were activities and dependencies the caregiver had to fulfill, and the subjective indicator was feelings of overload. The caregiving demands often led to other stressors and problems called *secondary stressors*. This categorization is meant to show that the interrelationship and chronic nature of caregiving is a complex experience in which the magnitude of caregiving demands leads to other stressors (Pearlin et al., 1990).

**Secondary stressors.** Secondary stressors are not considered less important than primary stressors, but result as a consequence of the primary stressors (Pearlin, 1989). Secondary stressors often are a result of role strains and intrapsychic strains experienced by the caregiver. Secondary role strains include the conflict that develops between the caregiving role and other family, job, and social roles, and economic strains that result from caregiving and role conflict (Pearlin, 1989; Pearlin et al., 1990). Intrapsychic strains can be classified as positive or negative and consist of those self-concept changes related

to mastery or self-esteem, or situational issues such as loss of self, role captivity, competence, or gain (Pearlin et al., 1990). Role captivity is different from other concepts associated with roles. It is one in which the caregiver is obligated to assume an unwanted role, and thus feels trapped (Aneshensel, Pearlin, & Schuler, 1993). Loss of self is defined by Skaff and Pearlin (1992) as “the constriction of self-identify or loss of the essence of oneself,” whereas gain is defined as “the sense of personal enrichment or character building that comes from having coped with a difficult situation” (p. 663).

In contrast to role theory, Skaff and Pearlin (1992) found that loss of self was more likely to be found in those with less social contact and lack of social roles, supporting the hypothesis that expansion of roles provides a mechanism for greater opportunity for increased self-concept. This, however, only addresses self-concept and does not necessarily examine other factors and other negative outcomes of caregiving. One interesting finding in the study was that no relationship was found between a loss of self and gain. As a result, Skaff and Pearlin (1992) concluded that loss of self and gain are discrete, independent concepts, both of which exist within the caregiving experience. In sum, role acquisition and role strain are factors that impact caregivers; however, questions remain as to the impact on the entire caregiving experience. As such, the impact of roles is viewed by the stress process model as a secondary stressor that can positively or negatively affect the caregiver.

**Mediators.** The mediators of coping and social support are often used as an explanation for why there are individual differences in the outcomes or manifestations of stress when similar sources of stress are experienced. Pearlin et al. (1990) acknowledged that these two mediators cannot account for all the variability in outcomes; however, they

believe they are major explanatory contributors. Coping, according to Pearlin et al. (1990), “represents behaviors and practices of individuals as they act on their own behalf” (p.590). Additionally, coping serves three functions: change the situation, manage the meaning of the situation, and manage the symptoms that result from the situation (Pearlin, 1989).

Social support is viewed as resources one actively uses to manage problems and is categorized as instrumental or expressive support. In addition, a social network is a structural concept which refers to the potential resource pool available to elicit social support. Also, it is the perception of social support that contributes to its mediation in the stress process (Pearlin, 1989). Stress is buffered, and possibly prevented or inhibited, by social support (Pearlin et al., 1990).

**Outcomes.** The outcomes that result from stress are typically related to individual well-being. They include both mental and physical health outcomes that can occur abruptly or gradually during the caregiving experience. The impact of these outcomes on the caregiver’s ability to provide care is of utmost interest to whether or not cessation of the caregiving role occurs (Pearlin et al., 1990). Thus, outcomes measured in research using the stress process model represent physical and/or mental aspects of well-being (Aneshensel et al., 1993) and often represent the biomedical perspective (Pearlin, 1989). Pearlin (1989) explained that outcomes mostly measured in research are limited and singular, but ideally research needs to discover the multiple outcomes that reflect the effects of life difficulties. In addition, Hunt (2003) described both negative and positive effects of caregiving. Pearlin (1990) acknowledged the positive gain and self-esteem derived from caregiving, but discussed this impact as a secondary stressor/strain that

contributes to outcomes and not an outcome itself. Therefore, both positive and negative outcomes of the caregiving experience need to be measured.

All frameworks provide a theoretical foundation to examine specific elements in the family caregivers' response to caregiving stress when providing care to a family member with a chronic illness. However, prior to selecting a theoretical perspective, the research questions, the unit of analysis, concept measurement, and analysis strategies need to be clearly articulated in the study design to select the most appropriate theoretical approach. In this study, the stress process model provides a broad theoretical framework that includes the study purposes and measures. It encompasses the majority of theoretical advantages the other theories offer. Finally, it underscores the importance of the stress process in examining the impact of caregiving demands on caregiver outcomes.

## **Study Concepts**

### **Caregiving Demands**

Caregiving demands are those activities and tasks that the caregiver engages in on behalf of the care recipient. They vary in number and intensity, and thus researchers are interested in how these demands are related to the differences seen in caregiver responses (Aneshensel et al., 1993). Caregiving demands or types of caregiving are typically categorized as activities of daily living (ADL) or instrumental activities of daily living (IADL). Examples of ADLs are getting in and out of bed, getting dressed, toileting, bathing, feeding, and administering medication. IADLs are those tasks related to managing finances, grocery shopping, housework, meal preparation, resource management, and transportation. Both categories have been shown to be related to caregiver burden (Garlo, O'Leary, H, & Fried, 2010; Y. Kim & Schulz, 2008; Wakefield,

Hayes, Boren, Pak, & Davis, 2012). Reinhard et al. (2012) reported that in addition to ADLs and IADLs, a third classification of caregiving demands faced by family caregivers included complex medical, nursing or clinical tasks. They found that for those family caregivers surveyed approximately half reported performing complex clinical tasks, including incontinence care, wound care, dietary supplementation, and medication management, often requiring both intravenous and injectable medications. These tasks were recently performed only by nurses in acute care facilities.

### **Social Support**

Social support is a concept often used in research; however, it lacks clarity in its definition (Chappell & Funk, 2011; Finfgeld-Connett, 2005; Hupcey, 1998). Although support is globally seen as beneficial, questions remain as to what constitutes social support, the system from which it is drawn, and whether or not specific social support resources are effective (Pearlin et al., 1981). Expanding this view, Hupcey (1998) discussed social support being viewed as positive or negative, recognizing that not all social support offered and received is perceived by the recipient as beneficial (Hupcey, 1998). Definitions of social support tend to revolve around various categories, including type of support, perceptions of the recipient, intentions of the provider, reciprocity, support networks, or a combination. Although the concept is often defined simply, its complexity is seldom captured. This complexity is related to the context and interactions necessary to request, accept and receive support (Hupcey, 1998; Williams, Barclay, & Schmied, 2004).

Social support is defined by Pearlin et al. (1981) as “the access to and use of individuals, groups, or organizations in dealing with life’s vicissitudes” (p. 340). Social

support, in contrast to social networks, refers to the resources used in dealing with life's problems. Whereas social networks are the total resources available to someone under stress, the effect of social support often depends on the context of the relationships from which it is obtained. As a result, perceived support is reported to have a buffering effect on stress (Pearlin, 1989).

In an analysis of the term *social support*, Finfgeld-Connett (2005) reported that two types of social support exist: emotional and instrumental. Emotional support includes those activities or behaviors viewed as comforting, aimed to decrease levels of uncertainty, anxiety, hopelessness, and depression. Instrumental support includes activities or services that are tangible, such as the provision of food or supplies. Antecedents to social support include need, social network, and social climate, all of which contribute to the interpersonal process influenced by the context and the reciprocal exchange of information (Finfgeld-Connett, 2005). Expanding this individual, or micro, perspective, Chappell and Funk (2011) added meso-level views, which included social institutions such as families, and macro-level views of social support in relation to gender and ethnicity. In a study of family caregivers, social support was conceptualized within functional, structural, and appraisal dimensions. The functional dimension characterizes the tangible aspects of support provided, the structural dimension refers to social networks, and the appraisal dimension represents the perception of social support provided (Sit, Wong, Clinton, Li, & Fong, 2004). Therefore, although social support is described differently in these studies, similar characteristics are exhibited in all of them that contribute to its conceptual meaning.

Social support has been reported to result in beneficial outcomes, including the reduction of distress, stress, loneliness, depression, cognitive decline, and biological risk. Additional positive effects include increased life satisfaction, psychological health, physical health, functional ability, survival, cognition ability, and adjustment to institutionalization (Chappell & Funk, 2011). In the caregiving literature, Bainbridge et al. (2009) found that higher levels of program accessibility and social support predicted less caregiver burden. Social support was also found to be the one predictor that contributed to both caregiver strain and caregiver satisfaction (Wakefield et al., 2012). Similarly, the availability of social support and satisfaction with it were positively correlated to adjustment and negatively correlated to distress (Fitzell & Pakenham, 2010). Chen and Greenberg (2004) also found that increased social support contributed to more reported positive outcomes of caregiving. In addition, Garlo et al. (2010) and Burton et al. (2012) found that the need or desire for more help was associated with higher caregiver burden. Overall, in a study of caregivers of stroke patients, Sit et al. (2004) found that caregivers often perceived more social support than actually present and that those with more tangible and social companionship had fewer health problems.

However, in a meta-analysis of 35 studies of social support in caregiver research, no association was found between the type of support (perceived or received) and caregiver adjustment. Additionally, no association was found when support was conceptualized as instrumental and socio-emotional (Smerglia, Miller, Sotnak, & Geiss, 2007). In this analysis, Smerglia et al. (2007) reported that 61% of caregivers did not find that social support had a positive impact on adjustment. Findings on the impact social support has on family caregivers are inconsistent. Therefore, questions exist as to whether

these differences could be attributed to the caregiving outcome measured or the instrument used to measure social support.

### **Coping**

Coping is defined by Pearlin and Schooler (1978) as “any response to external life strains that serves to prevent, avoid, or control emotional distress” (p. 3). The authors asserted that clarification of the concepts between social resources, psychological resources, and coping responses are necessary. Social and psychological resources assist in developing coping mechanisms. Social resources are the available personal networks from which support is drawn. Psychological resources are those internal resources, such as personal characteristics or traits, which enable one to handle life strains (Pearlin & Schooler, 1978). Resilience is a trait which could be viewed as a psychological resource. Pearlin and Schooler (1978) further explained that coping responses are those things people do to manage the life strains faced in their different roles. In their study of 2300 individuals, coping responses were categorized in three areas: responses that change the stressful situation, responses that control the meaning of the situation, and responses that control the stress itself after it has occurred. They also contend that having a variety of coping skills is more important than having a particular coping response when dealing with life strains (Pearlin & Schooler, 1978). Coping methods, therefore, vary based on the problems people face in their social roles (Pearlin et al., 1981).

This categorization is similar to the problem-focused and emotion-focused coping categories proposed by Folkman and Lazarus (1988). Problem-focused coping strategies are used to alter the stress source, whereas, emotion-focused coping is used to reduce or manage the emotions associated with the stressful event (Carver, Scheier, & Weintraub,



1989). Park and Folkman (1997) added an additional category, meaning-focused coping, to enhance the appraisal elements in Lazarus's model to better understand how global and situational meaning impact the process of coping with stress. This type of coping enables the meaning of significant events in caregivers' lives to be transformed. Therefore, both conceptualizations of coping are similar.

Coping is typically viewed as a mediator of stress, both broadly (del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; Folkman & Lazarus, 1988; Lim & Zebrack, 2004; Pearlin et al., 1981; Pearlin et al., 1990; Pearlin & Schooler, 1978) and specifically, in relation to caregiving (Barbosa, Figueiredo, Sousa, & Demain, 2011; Kneebone & Martin, 2003; Lim & Zebrack, 2004; Pearlin, Aneshensel, & Leblanc, 1997; Pearlin et al., 1990). Some studies found differences in the associations between specific types of coping and selected caregiver outcomes (Barbosa et al., 2011; Chronister, Chan, Sasson-Gelman, & Chiu, 2010; Lim & Zebrack, 2004). Barbosa et al. (2011) for example found that problem focused coping was useful by both primary and secondary caregivers, whereas, emotion focused strategies were not. Thus, the authors concluded that coping methods were viewed differently by the type of caregiver; whether primary or secondary. In addition, in a review that studied coping in family caregivers, Lim and Zebrack (2004) found the coping was viewed as a mediator in five studies and a predictor in four studies, both a predictor and mediator in two studies, and showed no relationship in another two studies. In addition, Chronister et al. (2010) found few links between coping and caregiver outcomes, and actually found a negative association between problem focused coping and caregiver quality of life.

Carver et al. (1989) felt the broad categorization of coping methods is too simplistic and, therefore, created an instrument comprised of coping dimensions to better encapsulate the various diversity in coping measures and to provide clarity among items. Additionally, these scales addressed coping methods theoretically and practically, including active coping, planning, suppression of competing activities, restraint coping, seeking instrumental social support, seeking emotional social support, positive reinterpretation and growth, acceptance, turning to religion, focus on and venting of emotions, denial, behavioral disengagement, mental disengagement, and alcohol-drug disengagement.

Therefore, although coping is accepted as being associated with stress, findings differ in regarding the relationship between coping and stress. These findings may be attributed to individual differences in the characteristics of the caregiver or caregiving contexts, and to the different categories in which coping methods and caregiver outcomes are classified and measured. Given these differences, questions, therefore, remain about how coping influences caregiver outcomes.

## **Caregiver Burden**

### **Incidence**

In 2009, an estimated 65.7 million people in the United States served as informal caregivers, with women providing the majority (66%) of this unpaid caregiving (National Alliance for Caregiving & AARP, 2009). Feinberg et al. (2011) asserted that the last 30 years of family caregiving research has revealed detriments related to the caregivers' own finances, health, social networks, and the ability to keep the loved one at home. This places a tremendous physical and economic burden on family caregivers. Research has

shown that 40%–70% of caregivers suffer from symptoms of depression, 17%–35% reported their health as poor to fair, and over 50% reported the presence of social isolation and stress (Feinberg et al., 2011).

### **Conceptual issues**

Caregiver burden is defined in multiple ways. As a multidimensional concept, its use in research lacks conceptual clarity (Bainbridge et al., 2009; Bastawrous, 2013). Hunt (2003) described issues related to similar terms used in the literature to reflect the negative conceptualizations of caregiving, including caregiver burden, hassles of caregiving, caregiver strain, and caregiver stress. In this view, Hunt (2003) explained that the multiple conceptions of caregiver burden contribute to its lack of conceptual clarity in the literature. Often, definitions of caregiver burden state that burden is a consequence or appraisal of caregiving, focusing on both the objective and subjective experiential domains (Hoffmann & Mitchell, 1998; Hunt, 2003). Objective burden comprises activities or tasks performed, whereas, subjective burden is related to emotions (Hoffmann & Mitchell, 1998). In a concept analysis of caregiver burden, Chou (2000) defined the concept as “an individual’s subjective perception of overload in one or more of four perspectives: physical, psychological, social, and financial through the caregiving process” (p. 405).

In addition to a lack of clarity, the literature suggests a lack of relevance to family caregivers. Caregiver burden is subjectively determined by a family member and thus its usefulness to reflect the impact on the caregiver is unclear (Bastawrous, 2013).

Caregiver burden was found to be minimally used as a term by caregivers to describe their experience. As a result, researchers reached the conclusion that the term was

irrelevant because caregivers may not perceive caregiving as a burden (Greenwood, Mackenzie, Cloud, & Wilson, 2009). Therefore, the concept may be limited in its application and thus may not reflect accurately the total caregiving experience (Bastawrous, 2013).

Caregiver burden differs in how it is conceptualized and thus examined in family caregiving research. Some view it as a primary stressor that the caregiver assesses subjectively (Bastawrous, 2013; Pearlin et al., 1990). Specifically, caregiving demands combined with various caregiver and care recipient characteristics contribute to burden. Burden in this context is viewed as a stressor which leads to negative caregiver outcomes. (Pearlin et al., 1990). In contrast, caregiver burden is also viewed as the caregiver's appraisal of the primary and secondary stressors, which then results in the caregiver outcomes (Chronister & Chan, 2006; Fletcher et al., 2012). Therefore, appraisal is conceptualized in this expanded model as an additional process between stressors and outcomes (Fletcher et al., 2012). Although not explicitly stated, appraisal is subsumed under the primary and secondary stressors in the stress process model in that the caregiver subjectively experiences caregiving as a stressor.

Finally, caregiver burden is also viewed as a consequence of caregiving (Hoffmann & Mitchell, 1998). Hunt (2003) defined caregiver burden as a negative effect of caregiving, thus implying it is an outcome. Bainbridge et al. (2009) conceptualized burden as the caregiver's response to caregiving demands; however, the authors contend that stress and strain are the "enduring consequences" (p. 538) contributing to conceptual confusion. As such, Bainbridge et al. (2009) used caregiver burden as the outcome variable studied based on its wide use in caregiver research and its reflection of the

multidimensional nature of the concept. This conceptualization may reflect the cyclical nature of demands, stress, and burden. Additionally, caregiver burden has been studied as both a predictor and outcome (Lim & Zebrack, 2004; Savundranayagam, Montgomery, & Kosloski, 2011). Lim and Zebrack (2004) reported in a critical review of caregiver literature from 1997 through 2004, that caregiver burden was a concept that was measured to reflect the outcome of quality of life in multiple studies. Finally, using the stress process model as a framework, Campbell et al. (2008) and Kim et al. (2012) both measured caregiver burden as an outcome. Based on this discussion, caregiver burden is a multidimensional concept which, based on its definition, can be considered a primary stressor, secondary stressor, or outcome in the stress process model. In this study, the category *caregiving demands* is viewed as the primary stressor with caregiver burden as one outcome that can lead to other positive and negative outcomes.

### **Factors impacting burden**

Multiple variables have been identified that contribute to the caregiver's experience of caregiver burden. Among these, noted variables include gender, financial impact, and relationship. Other variables considered include the type of caregiving performed and the length of time care is given. It is reported that over 30% of caregivers experience high rates of burden and stress, with women reported at higher risk than men (National Alliance for Caregiving & AARP, 2009). In support, several studies found that women caregivers reported increased burden compared to men (Akpınar, Küçükgüçlü, & Yener, 2011; del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012; Papastavrou, Tsangari, Kalokerinou, Papacostas, & Sourtzi, 2009; Ussher & Sandoval, 2008). However, in a meta-analysis of gender differences in caregiving

literature, including 229 studies, Pinquart and Sörensen (2006) found that differences in the amount of burden attributable to gender were small to very small. Additionally, Bainbridge et al. (2009) found that gender was associated with caregiver burden; however, it did not contribute significantly to the model due to its covariance with age. Therefore, these inconsistencies suggest that further examination related to gender differences is warranted.

Financially, caregivers suffer due to lost wages and the need to leave the workforce. Income-related losses are estimated on average to be more than \$300,000 over a caregiver's lifetime. Interestingly, women caregivers of aging parents have an increased risk of living in poverty and receiving public assistance in their old age. Nationally, it is estimated that the cost of family caregiving has risen from \$350 billion in 2006 to \$450 billion in 2009. The monetary increase is attributed to the aging population and increased need for family caregivers. Specifically during these years, there has been a 23% increase in the number of family caregivers, a 9% increase in the number of care hours provided, and a 43% increase in the cost per hour estimate (Feinberg et al., 2011). These figures indicate a significant financial burden for family caregivers.

Conflicting evidence exists regarding how the type of relationship between the caregiver and care recipient contributes to caregiver burden. In a comparison of burden scores, Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, and López-Pousa (2010) and Given et al. (2004) found that overall burden was greater with adult children caregivers compared to spouse caregivers; however, others did not (Call, Finch, Huck, & Kane, 1999; Pinquart & Sörensen, 2011). One explanation for the differences in results may be related to the complexity and context of the roles in caregivers' lives.

Furthermore, family caregivers experience stress as the demands and roles change in the relationship. As the stress of caregiving accumulates, caregiver burden occurs. Shyu (2000) and Wuest (2001) discussed caregiving in relation to its multiple demands. Shyu (2000) found the theme of “finding a balance point” as the process that caregivers identified to “achieve or preserve equilibrium in caregiving while facing competing demands” (p. 36). In addition, women caregivers responded to the multifaceted, changing, and competing demands of caring (Wuest, 2001; Wuest & Hodgins, 2011). Therefore, it is reasonable to conclude that it is not the sheer number of roles, but the complexity and changing dynamics within the roles that contribute to increased burden.

In addition, characteristics of the caregiving experience, including the type of caregiving and the length of time care was provided, contributed to the development of caregiver burden. Some researchers have reported that tasks involving ADL and IADL increase caregiver burden (Garlo et al., 2010; Y. Kim & Schulz, 2008; Wakefield et al., 2012). In contrast, Burton et al. (2012) and Campbell et al. (2008) found that ADL and IADL impairment did not contribute to caregiver burden. However, in Burton’s (2012) study this finding could be explained by the fact that only 23% of caregivers in the sample provided ADL and IADL support for the care recipient. Therefore, the association of ADL and IADL with caregiver burden is inconclusive.

Time spent per week assisting with caregiving tasks was associated with increased burden (Bainbridge et al., 2009; Savundranayagam et al., 2011). Kim et al. (2012) found that caregivers who reported spending more hours providing more care experienced higher levels of burden. However, Garlo et al. (2010) found that although burden increased somewhat over time, the relationship between time and burden was not

significant. In a study of stroke crisis across trajectory, family caregivers reported that transition to home and provision of care created another crisis. Caregivers felt overwhelmed by the preparation and training needed to provide care 24 hours a day, in addition to the financial hardships and care coordination required. The amount of care needed and the caregiver's ability to provide the care impacted how well the caregiver adjusted (Lutz, Young, Cox, Martz, & Creasy, 2011). Therefore, factors impacting the caregiver's experience are individual and varied and thus result in various levels of burden.

In summary, caregiver burden is a multidimensional concept that is reported to negatively impact family caregivers. The concept has been defined differently in the literature and thus results in conceptual confusion. Various demographic characteristics and caregiving factors have been shown to have mixed association with caregiver burden. Caregiver burden is a concept that addresses only the negative aspects of caregiving outcomes and thus may not be the best concept to reflect the family caregiver's experience. In response, it is important that research continues to explore and examine the family caregiver's experience so that interventions can be instituted that address factors that promote positive outcomes and prevent negative ones. Compassion fatigue is an alternative concept to consider in this population and may better represent the overall caregiving experience.

### **Compassion Fatigue**

Compassion fatigue is a term that is often ascribed to Joinson (1992), who first used it in an effort to describe the burnout of emergency room nurses. The concept was used to describe nurses' feelings related to caring for patients who had experienced



trauma. However, confusion about its definition remains. Multiple related concepts have been used in the literature, including secondary traumatic stress, vicarious traumatization, countertransference, and burnout. Compassion fatigue is often cited as an additional term for secondary traumatic stress (STS). By definition, STS is similar to posttraumatic stress disorder (PTSD) except that the caregiver experiences the traumatic event through the patient's description of the experience (Figley, 1995, Gentry, 2002).

Compassion fatigue is viewed by Stamm (2010) as the negative consequence of being a helper. Stamm conceptualizes it as comprising both burnout and secondary traumatic stress. Burnout is described as exhaustion, frustration, hopelessness, anger and depression. Often, burnout is gradual and associated with the feeling that one's efforts make no difference in outcomes. Burnout often results when workload is high and one is in a nonsupportive environment, whereas secondary traumatic stress is associated with the feelings of fear and work-related trauma which result in sleep disturbances, intrusive images, and avoidance (Stamm, 2010). However, other authors differentiated the concept of compassion fatigue from both burnout (McHolm, 2006; Rourke, 2007; Sabo, 2006) and secondary traumatic stress (Meadors, Lamson, Swanson, White, & Sira, 2009; Najjar, Davis, Beck-Coon, & Carney Doebbeling, 2009). Similar to Stamm (2010), Adams, Boscarino, and Figley (2006) stated that burnout and secondary trauma are critical features of compassion fatigue but that compassion fatigue is a distinct concept that may be interrelated and share common characteristics with burnout and secondary traumatic stress.

Specifically addressing compassion fatigue, Figley (2002) proposed that 10 variables—empathetic ability, empathetic concern, exposure to the client, empathic

response, compassion stress, sense of achievement, disengagement, prolonged exposure, traumatic recollections and life disruption—interact to contribute to the development of compassion fatigue. Both Figley (1995) and Coetzee and Klopper (2010) acknowledged that progressive and cumulative stress increases the risk of compassion fatigue.

Although compassion fatigue is most often associated with professional caregivers, the appropriateness and application to informal family caregivers is deemed relevant. As healthcare is shifted to community and home settings, the complexity of care leads one to compare the family caregiver's role to that of a professional nurse.

Reinhard, Given, Petlick, and Bemis (2008) stated that the standard ADL and IADL tasks often cited as those performed by family caregivers no longer reflect the complexity of care required and thus provided. Similarly, Reinhard et al. (2012) stated that the role of the family caregiver has expanded significantly and now includes complex clinical tasks once only performed by nurses. This comparison warrants exploring whether the negative outcomes associated with nursing care, such as compassion fatigue, are present in family caregivers. This shift in the caregiver's role indicates a need for analysis of compassion fatigue in relation to nursing and applied to family caregivers.

### **Nursing**

Compassion fatigue was found in 30 nursing sources within the databases of CINAHL, Academic Search Complete, and Psych Info. Articles included were those that addressed compassion fatigue in the nursing profession only. The majority of the sources identified were review articles that focused on the description of compassion fatigue and its importance in nursing. Secondly, 14 research studies were found that included quantitative, qualitative and mixed methods designs. Additional articles reported results

of intervention projects with anecdotal observations. Collectively, the qualitative articles focused on experiences of nurses and their descriptions of compassion fatigue that were mostly obtained through semistructured interviews. The quantitative studies ( $n = 5$ ) and mixed methods ( $n = 3$ ) were mostly survey descriptive designs that utilized predominantly the Professional Quality of Life Scale (ProQOL) instrument.

### **Review of literature**

Compassion fatigue in nursing review articles typically focused on an overview of the concept, symptoms, risk factors and/or interventions to prevent compassion fatigue. Often articles either presented compassion fatigue singularly as a concept (Coetzee & Klopper, 2010; Joinson, 1992; Lombardo & Eyre, 2011; Sabo, 2006); in conjunction with several concepts (Keidel, 2002; Sabo, 2011; Sabo, 2008) or differentiated compassion fatigue from similar concepts (Bush, 2009; McHolm, 2006). Conceptual clarification seemed to be a primary focus of study as often the term was similarly discussed in relation to burnout, vicarious traumatization, and secondary traumatic stress. Collectively, often cited in relation to compassion fatigue are how the primary characteristics of empathy and stress contribute to the development of compassion fatigue (Figley, 1995).

Theoretical frameworks cited in connection with compassion fatigue involve the stress process framework that focuses on the use of empathy in the therapeutic relationship when exposed to the suffering of others (Bush, 2009; Sabo, 2006). Lombardo (2011) cited Watson's theory of human caring as a relevant theory as empathy and the nurse patient relationship are foundational. Thus, an empathic nurse-patient relationship is required for professional nursing practice but also can predispose a nurse to the

negative effects of compassion fatigue. In addition, Sabo (2006) introduced the idea that other concepts besides empathy, such as hope and resilience, may impact the process. Bush (2009) further cited stress and coping theories that typically focus on the individual response to the stress instead of the stressor as having primary importance. This lends itself to concentrating on coping mechanisms as a method for intervention. Similarly, many of these theories and concepts have been explored in relation to family caregivers and research related to caregiver burden.

Most often associated with compassion fatigue in the nursing literature is burnout. McHolm (2006) differentiated burnout and compassion fatigue. Both, she acknowledged, result from work-related stress. Burnout, however, is a response to the work environment and conditions, whereas, compassion fatigue is a response to the close identification with the people (McHolm, 2006). Yoder (2010) found in her study of nurses that work-related triggers were mostly closely related to burnout than were personal triggers. Furthermore, Sabo (2006) suggested that burnout can occur in any work environment without the presence of a relationship, whereas compassion fatigue is dependent on a relationship. However, it is unclear what role this relationship, founded on empathy and engagement, plays in compassion fatigue. In contrast, Keidel (2002) conceptualized burnout and compassion fatigue as synonymous, but viewed compassion fatigue as a “less abrasive term” (p. 200). Therefore, although there are differences in how burnout and compassion fatigue are described and compared, compassion fatigue is a more inclusive term that recognizes the importance of the relationship in the development of negative outcomes from caregiving. Since an established relationship between the caregiver and care recipient exists, this view may provide support for the use of term *compassion fatigue* in

reference to family caregivers in place of *caregiver burden*. As Bastawrous (2013) stated, caregiver burden was not a term family caregivers typically used to describe their experience.

In an effort to illustrate the concept of compassion fatigue, authors often used clinical scenarios to provide a richer description of various concepts. Coetzee and Klopper (2010) used Walker and Avant's concept-analysis strategy, to apply model, borderline, and contrary cases to provide conceptual clarity. Sabo (2006) used an evolving clinical scenario to illustrate the concepts of burnout, compassion fatigue, and vicarious traumatization. In the clinical scenario related to burnout the focus was on work-related stressors such as low staffing and increased patient complexity. In the depiction of compassion fatigue, the nurses' relationships to patients and families are highlighted in response to patient crises and how nurses are personally affected by patient issues. Bush (2009) used an example of a nurse who over time experienced feelings of loss of control, helplessness, and hopelessness in response to work- and patient-related factors. In addition, the nurse's personal life was affected as these feelings interfered with work, family and her personal outlook as she began to have nightmares and began to feel incompetent and isolated. These illustrations of the concept in the context of clinical scenarios better enable one to conceptualize the meaning of compassion fatigue. Additionally, conceptual analysis strategies were also used to illustrate the concept of compassion fatigue in family caregivers (Lynch & Lobo, 2012).

Nurses are often professional caregivers at risk for compassion fatigue. Bush (2009) reported that "Nurses who are idealistic, highly motivated, and committed" (p. 26) are at risk for compassion fatigue. Keidel (2002) supported this view by noting that some

personalities are more susceptible to burnout and compassion fatigue than others: especially those overly conscientious, perfectionistic, and self-giving. In addition, those nurses who experience cumulative losses may even be at higher risk than other nurses (Bush, 2009; Keidel, 2002). In addition, Coetzee and Klopper (2010) further clarified that “compassion fatigue is the final result of a progressive and cumulative process that is caused by prolonged, continuous, and intense contact with patients, the use of self, and exposure to stress” (p. 237). Similar to relationships nurses have with patients, family caregivers often have long, personal caregiving relationships with the care recipient which evolves over time. It was estimated that 86% of family caregivers reported caring for a relative and 55% have served in this role for three or more years with the average duration of care lasting 4.6 years. In addition, 15% reported caring for the care recipient 10 or more years (National Alliance for Caregiving & AARP, 2009). It is clear from these studies that the characteristics of prolonged, continuous, and intense relationships also apply to family caregivers.

### **Qualitative research**

Qualitative research studies on compassion fatigue in nursing have explored its causes, risk factors, symptoms, and preventive strategies. Perry, Toffner, Merrick, and Dalton (2011) studied compassion fatigue among oncology nurses and found common themes surrounding the definition, cause, outcome, and factors that both worsened and lessened compassion fatigue. Causes of compassion fatigue that were reported included a lack of support, lack of knowledge, and lack of time to give high quality care (Perry et al., 2011). Family caregivers often reported that a lack of knowledge about caregiving and feeling unprepared contributed to their stress (Reinhard et al., 2012). The research

shows that only 19% of caregivers received training and 78% reported needing more information related to caregiving (National Alliance for Caregiving & AARP, 2009).

Although compassion fatigue is most often associated with professional caregivers, the appropriateness and application to family caregivers is deemed relevant. As healthcare is shifted to community and home settings, the complexity of care leads one to compare the family caregiver's role to that of a professional nurse. Family caregivers of those care recipients with chronic illness perform care that is expanding and including more complex clinical tasks that were once performed only by professional caregivers (Reinhard et al., 2012). This comparison warrants exploring whether the negative outcomes associated with nursing care, such as compassion fatigue, is present in family caregivers. Given these similarities, compassion fatigue needs to be analyzed globally, in relation both to nursing and to family caregivers.

In addition to these causes, factors that worsened compassion fatigue included being unable to ease suffering, coexisting physical and emotional stresses, and excessive emotional attachment or involvement (Perry et al., 2011). Similarly, Melvin (2012) found support in a study of hospice nurses for these factors as nurses stated that the risk of compassion fatigue could worsen if they allowed the exposure to dying patients to consume them. Other descriptions referred to multiple losses, feeling too responsible, and needing to separate. Maytum, Heiman, and Garwick (2004) studied compassion fatigue and burnout as a joint experience and identified work and personal triggers associated with compassion fatigue. The most reported personal trigger, overinvolvement or crossing professional boundaries, best supports other findings. Additional personal triggers found were taking things too personally, unrealistic expectations of self, and

outside or family commitments/problems. Yoder (2010) in a mixed methods study, used Maytum et al. (2004) trigger categories of compassion fatigue and reported that the theme of caring seems most related to compassion fatigue, as nurses reported the “inability to rescue the patient” (p. 195). In contrast, work-related triggers seemed most closely related to burnout. Therefore, based on the reviewed literature excessive emotional attachment or overinvolvement is a major factor that contributes to the development of compassion fatigue in nurses. This finding also applies to family caregivers. It is the shared relationship with shared emotions and experiences that may put a family caregiver at increased risk for psychological and physical illness (Family Caregiver Alliance, 2012). Similar to nurses, informal caregivers also expressed emotional attachment and overinvolvement as factors that impact their role as a family caregiver (Ward-Griffin, St-Amant, & Brown, 2011).

Symptoms and coping strategies for compassion fatigue were also described in the literature. Perry et al. (2011) reported symptoms of profound fatigue, negative effects on personal relationships, and consideration of leaving the profession as associated with compassion fatigue. Similarly, Maytum et al. (2004) found that nurses reported fatigue and lack of energy as key symptoms of compassion fatigue. In response, coping strategies were clearly identified to treat or prevent compassion fatigue. Perry et al. (2011) found that factors that lessened compassion fatigue included peer support, work-life balance, connecting with others, acknowledgment, and maturity and experience. In addition, Melvin (2012) reported that nurses described the need to set professional boundaries and adopt positive coping mechanisms, including exercise, reflection, supportive services from peers and supervisors, in order to continue to work and provide end-of-life care.



Maytum et al. (2004) supported both these findings as they delineated coping strategies into categories including short- and long-term personal and work-related strategies. Similar strategies identified included supportive networks, professional boundary development, work-life balance by taking time for self, self-care activities such as exercise, and time to debrief formally and informally.

As coping and social support are identified globally as impacting stress responses, both formal, professional caregivers and informal, family caregivers are impacted by these factors. Informal caregivers often have to manage their own work commitments with the demands of caregiving, which places an additional stress on the family caregiver thereby requiring increased reliance on coping mechanisms. Similarly, formal caregivers reported the desire to leave the profession, while informal caregivers reported the need to adjust work arrangements, including both reductions in work hours and leaving employment. Changes and adjustments to work schedules are reported by 69% of family caregivers to manage caregiving demands (Feinberg et al., 2011).

### **Quantitative Research**

Quantitative compassion fatigue research has predominantly focused on measuring compassion fatigue using the Professional Quality of Life (ProQOL) scale by Stamm (2010) or other previous versions of the scale. The scale assesses both the positive and negative outcomes of caregiving with respect to compassion satisfaction and compassion fatigue. The three subscales include compassion satisfaction, burnout, and secondary traumatic stress. Cut scores provide an indicator of level of risk for each of the subscales that overall can indicate one's level of risk for exhibiting compassion fatigue as low, moderate, or high (Stamm, 2010). In the studies found, the majority of nurses fell

into the moderate or high-risk category for compassion fatigue (Abendroth & Flannery, 2006; Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Potter et al., 2010; Yoder, 2010). In contrast, Frank and Karioth (2006) found a low risk of compassion fatigue among public health nurses after a natural disaster. This disparity of results may be related to the time of exposure to patients. For example, Frank and Karioth (2006) studied public health nurses after providing care for hurricane victims for two weeks or less, whereas, Abendroth and Flannery (2006) studied hospice nurses, Potter et al. (2010) studied oncology nurses, and Yoder (2010) and Hooper et al. (2010) studied a cross-section of home care and hospital nurses, including emergency, intensive care, medical surgical, and oncology nurses. Therefore, questions arise as to whether the duration of care or the particular characteristics of the patient population most influence compassion fatigue. Hooper et al. (2010) specifically found that 86% of emergency nurses exhibited a moderate to high risk of compassion fatigue; however, this was not significantly different from the other specialties. Additionally, Yoder (2010) found fairly consistent results of moderate risk for compassion fatigue across all specialties, but found compassion satisfaction was higher in intensive care nurses compared to emergency nurses.

In addition, variables that contributed to the risk of compassion fatigue through multiple regression included stress, trauma, anxiety, life demands, and excessive empathy leading to blurred professional boundaries (Abendroth & Flannery, 2006). Potter et al. (2010) did not find a significant relationship between years of experience and compassion fatigue risk; however, groups that had 6 – 10 years' experience had the highest percentage of high risk of burnout and low compassion satisfaction scores. Also those with 11 – 20 years' experience had the highest percentage of those at high risk for

compassion fatigue. However, Abendroth and Flannery (2006) found fairly equal distribution of low-, moderate-, and high-risk of compassion fatigue related to years of general experience and years of hospice experience. In regards to personal life demands, Frank and Karioth (2006) supported Abendroth and Flannery's predictor of life demands when they found that risk of compassion fatigue was positively correlated to personal/family disruption ( $r = .29, p = .005$ ).

### **Family caregivers**

Literature found for compassion fatigue in family caregivers included four published sources: two qualitative studies, one concept analysis, and one review article. Literature specifically related to compassion fatigue and family caregivers is limited. However, recent reviews and research are beginning to explore the presence of compassion fatigue in this population. Lynch and Lobo (2012) analyzed the concept of compassion fatigue in family caregivers through a Wilsonian concept analysis to determine whether the concept is relevant for family caregivers. The results provided conceptual clarity and indicated that even though the concept is predominantly applied to professional caregivers; it may be relevant for family caregivers. Similarly, in an analysis of the literature, Day and Anderson (2011) concluded that, based on the definitions of compassion fatigue and the symptoms exhibited by family caregivers of dementia patients, a risk for compassion fatigue exists. Finally, both qualitative studies ( $n = 2$ ) found symptoms in family caregivers that are associated with compassion fatigue (Perry, Dalton, & Edwards, 2010; Ward-Griffin et al., 2011).

In those qualitative studies, Perry et al. (2010) found the key themes of role engulfment and enveloping sadness expressed by family caregivers of those in long-term

care facilities. The researchers then compared the reported experiences to elements in Figley's compassion fatigue model and found multiple elements present, two of which included an empathetic response and the presence of compassion stress. These characteristics were evident as participants described an inability to disengage from their loved one's suffering and the inability to feel any satisfaction with their contribution to the relief of that suffering. However, one element not specifically found in the data included the presence of traumatic memories. However, the authors questioned whether these memories could have been present, but not shared with the researcher (Perry et al., 2010).

This theme of the inability to disengage was also found in a study by Ward-Griffin et al. (2011) of the experience of nurse daughters with double-duty caregiving. Not only did they report blurred professional and personal boundaries in the provision of care, they found that the nurses' strong emotional attachment to their parent contributed to a preoccupation with their parent's care, which led to their absorbing their parent's pain and suffering. The nurses reported these feelings as different from the ones experienced with the professional care they provide. Similar conclusions were drawn that this overidentification and empathetic response was associated with compassion fatigue. As noted in the previous study, traumatic memories were not specifically addressed; however, the authors did conclude that the more the nurse daughters identified with their parent's situation, the more likely they would assume feelings similar to their parents.

However, compassion fatigue represents only one dimension of the caregiving experience. Compassion satisfaction is a term that represents the positive aspect of

caregiving. Stamm (2010) proposed the concept of professional quality of life to represent the broader experience of work as a helper. Professional quality of life represents both the positive (compassion satisfaction) and the negative (compassion fatigue) aspects of caregiving. The scale used to measure the two concepts is the Professional Quality of Life (ProQOL) scale. The scale was originally created by Figley in the 1980s and was called the Compassion Fatigue Self-Test. Since Stamm and Figley collaborated, the instrument has undergone multiple revisions (Stamm, 2010).

### **Compassion Satisfaction**

Compassion satisfaction is viewed as the positive outcome of the caregiving experience. It reflects the positive feelings that result from one's ability to help others. It is often viewed as being altruistic and evoking the sense of feeling good about being able to help, and gaining pleasure from the caregiving work (Stamm, 2010). However, this concept as proposed by Stamm (2010) and measured by a subscale in the ProQOL has only been measured in professional caregivers. Amongst the family caregiving literature, research into the positive outcomes for caregivers is growing, although limited. Positive outcomes reported included self-affirmation, enjoyment, and satisfaction (Chappell & Funk, 2011). Additionally, Greenwood et al. (2009), in a review of stroke caregiver qualitative research, found positive references that included fulfillment, feeling good, pride, and satisfaction. In addition, Chen and Greenberg (2004) found that family caregivers reported personal strengths, new insights, and greater intimacy with others as a result of caregiving. In sum, findings from the family caregiving literature related to positive outcomes support the definition of compassion satisfaction.

In the nursing literature, compassion satisfaction has been shown to protect against the negative outcomes of caregiving (Hooper et al., 2010; Neville & Cole, 2013; Yoder, 2010). Compassion satisfaction was found in a study of nurse caring and work environment to contribute to 28.7% of the variance in caring. One study using Maslow's hierarchy of needs found that compassion satisfaction was an indicator of self-actualization (Burtson & Stichler, 2010). In addition, Hooper et al. (2010) found that emergency nurses with higher compassion satisfaction scores had lower levels of burnout. The authors then concluded that higher compassion satisfaction scores helped to balance the negative impact of caring for ill clients. These results are supported by Slocum-Gori, Hemsworth, Chan, Carson, and Kazanjian (2013). Additionally, Yoder (2010) found in a mixed methods study that those with higher compassion satisfaction reported feelings of being "fulfilled," "being happy," "being me," and being "connected to others" (p. 193). In addition to these positive statements, the participants reported fewer negative outcomes associated with caregiving (Yoder, 2010). In relation to family caregivers, Day and Anderson (2011) similarly reported that a sense of fulfillment can protect a family caregiver from compassion fatigue. As discussed, the caregiving experience results in both positive and negative outcomes, which can exist simultaneously (Andrén & Elmståhl, 2005; Chappell & Funk, 2011). Andrén and Elmståhl (2005) further added that since the negative consequence of burden did not impact the level of satisfaction, both represent different aspects of the caregiving experience. Therefore, if these dichotomous outcomes co-exist, then research needs to examine the range of caregiver experiences to fully understand and develop strategies to

provide caregiver support so that both the care recipient and caregiver remain as healthy as possible, for as long as possible.

In summary, family caregivers experience changing and competing demands in their caregiving role that can result in both positive and negative outcomes, such as compassion satisfaction and compassion fatigue. The stress process model provides a theoretical framework to study the family caregivers' experience related to background context, stressors, mediators, and outcomes. Caregiver burden is a common concept studied in relation to family caregivers; however, this concept lacks conceptual clarity and may not accurately reflect the caregiver's experience. Compassion fatigue is proposed as an alternative concept to represent the negative outcomes that result from the progressive accumulation of stress caused from caregiving demands. This concept, while similar to caregiver burden, is relevant to family caregivers as it is founded on empathy and an established relationship. Although questions may arise as to whether compassion fatigue and caregiver burden are synonymous or distinct concepts, compassion fatigue may be a more acceptable, less abrasive, and thus more applicable term for family caregivers.

### **Chapter Three: Methods**

The purpose of this study was to examine the concept of compassion fatigue among family caregivers using a cross sectional descriptive survey design with a convenience sample. A second purpose was to explore the relationship between caregiver burden and compassion fatigue and to determine which characteristics were predictive for the level of compassion fatigue in primary family caregivers for care recipients with chronic disease.

The specific aims of the study were to examine the positive (compassion satisfaction) and negative (compassion fatigue) outcomes of caregiving in family caregivers and identify factors including caregiver burden, social support, coping, length of time caregiving, caregiving demands, and background context factors that contributed to the level of compassion fatigue.

The following five research questions guided the study:

1. What is the level of compassion fatigue and compassion satisfaction in family caregivers?
2. What is the relationship between caregiver burden and compassion fatigue?
3. Do background context factors (age, gender, ethnicity, employment status, caregiver education, caregiver relationship, income) contribute to differences in compassion fatigue scores?
4. Do caregiving demands, length of time caregiving, social support, coping, and caregiver burden contribute to the prediction of compassion fatigue in family caregivers?



5. Do caregiving demands, length of time caregiving, social support, coping and caregiver burden contribute to compassion satisfaction in family caregivers?

### **Research Design**

To answer these research questions a cross sectional descriptive survey design with a convenience sample was used to examine the relationships of the study concepts. A cross sectional descriptive survey design was chosen for this study because of the benefits which included the ability to reach a large number of participants in a cost effective manner and because it yielded a rapid turnaround time for data collection (Creswell, 2009). However, recognition of difficulties using surveys were considered such as survey error related to coverage, sampling, non-response, and measurement (Dillman, Smyth, & Christian, 2009).

In an effort to best address these issues, a mixed-mode survey design was used for this study to better ensure coverage and decrease the non-response rate. A mixed-mode survey design recognized that there are personal preferences in how one would like to be surveyed and increasing response rates is an important issue. However, Dillman, Smyth, and Christian (2009) reported that use of mixed mode surveys do not necessarily increase response rates when offering participants a choice in modes, but may actually decrease response rates. Therefore, they suggested that use of a primary mode is preferable, with offering an alternative mode when participants wish to participate, but are unable using the primary mode. Additionally, measurement error may be decreased if survey items are ordered and constructed in both modes identically (Dillman, Smyth, & Christian, 2009). For this study, a web based survey was the primary method of survey. However, a paper

survey was available due to the possibility of some family caregivers either not being comfortable with the technology or not having access to a computer/internet.

Therefore, the study had the following limitations:

1. The cross sectional design examined family caregivers at one point in time that may have not accurately reflected the positive and/or negatives outcomes under study.
2. The sample was limited to family caregivers in one southern state. This convenience sample located in a specific geographic area may limit the generalizability of the results.
3. Variables not examined in this study may have impacted the results. They may include: feelings of obligation, past poor relationship with the care recipient, and unreported psychological problems such as depression.

### **Setting**

Potential participants were recruited from organizations supporting family caregivers in North Carolina. Selected organizations were contacted who supported family caregivers throughout or during a specific time period of care recipient's illness trajectory. Organizations who agreed to participate in the recruitment of subjects included a family caregiver support program serving a large metropolitan county, a hospice and palliative care organization providing home and residential care that serves 8 adjacent counties, a foundation providing home care services for Amyotrophic Lateral Sclerosis (ALS) patients, and the Multiple Sclerosis Society of North Carolina. Using family caregivers caring for patients with various chronic diseases was intended to increase

generalizability of findings relative to chronic diseases, even though it is recognized that participants are limited to one geographic region.

### **Sample**

The targeted sample for the study was primary family caregivers of adults diagnosed with chronic disease who received at least a minimum level of support for activities of daily living (ADL) and/or instrumental activities of daily living (IADL) from a primary family caregiver.

According to the Australian Department of Health (2012):

Chronic disease has been defined as illness that is prolonged in duration, does not often resolve spontaneously, and is rarely cured completely. Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability. Features common to most chronic diseases include:

- complex causality, with multiple factors leading to their onset
- long development period, for which there may be no symptoms
- a prolonged course of illness, perhaps leading to other health complications
- associated functional impairment or disability (para. 1).

ADLs consisted of those tasks such as bathing, dressing, toileting, transferring, continence, and feeding (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) for which the family caregiver assisted the care recipient. IADLs included those tasks such as use of the telephone, shopping, food preparation, housekeeping, laundry, transportation, medication management, and finances (Lawton & Brody, 1969).

For this study the calculation of sample size was computed a priori using G\*Power Version 3.1.2 for each selected statistical test used. For anticipated tests, it was estimated that a minimum of 159 participants was needed (Faul, Erdfelder, Lang, & Buchner, 2007).

**Power analyses.** Although a descriptive study, an appropriate sample size was needed to answer research questions to examine the relationships between study variables and predict outcomes. In order to estimate an appropriate sample size for the study, a power analysis was conducted. Sample size can be determined by using Cohen's tables for specific statistical tests or by using computer applications to estimate the sample size for known alpha, effect size and power. Cohen (1990) reported that power analysis is dependent on four criterion; alpha significance level, the sample size, effect size and the power of the test. The importance of these criteria is that any one criterion is a function of the other in determining the probability of obtaining a significant result. Therefore, the sample size can be estimated once the researcher has determined the acceptable risk for the other criterion (Cohen, 1990; Munro, 2005).

An alpha significance level of 0.05 was determined by deciding the acceptable risk for the probability of a type I error. Pallant (2013) described type I errors as when the null hypothesis is rejected, when it is true. Therefore, a claim of differences is made when there are none. However, if the alpha is set too low to address a potential type I error, the power of the test is decreased and a higher risk of a type II error results. A type II error occurs when a false null hypothesis is accepted as true, even when significant results exist. Therefore, a common alpha of 0.05 is often determined acceptable, but should be based on research questions and acceptable risk (Munro, 2005). Cohen (1990) refers to

the standard 0.05 as a “convenient reference point along the possibility-probability continuum” (p.1311).

A medium effect size was used for the power analyses since no previous research was found regarding compassion fatigue and compassion satisfaction in family caregivers. Effect size is considered the magnitude or impact of the independent variable on the dependent variable. Although, effect size should be based on previous research if available, estimates of moderate effect are often used (Munro, 2005). This measure provides an indication of whether the finding is important by determining the strength of association (Pallant, 2013).

The power of the test was set at 80%. Power is the probability of detecting a difference, if a difference really exists. It is the likelihood of rejecting the null hypothesis. A recommended level is often considered 80% (Munro, 2005). Cohen (1992) justified this level due to the idea that in scientific research it is “more serious to make a false positive claim (Type I error) than a false negative one (Type II error)” (p. 100).

Calculation of sample sizes was computed using G\*Power Version 3.1.2 (Faul, Erdfelder, Lang, & Buchner, 2007) using the selected values described. A sample of 84 is needed for a correlation with a  $p < .05$ , power of .80 and a medium effect size. The sample size of 128 is needed for a t-test with  $p < .05$ , power of .80 and a medium effect size. The sample size of 159 is needed for an ANOVA with 3 groups with  $p < .05$ , power of .80 and a medium effect size. The sample size for multiple regression is based on 15 participants per predictor with an estimated model of 5 predictors yields a sample of 75 (Pallant, 2013); whereas, G Power estimates a sample needed of 92. Therefore, a minimum total sample size of 159 was needed for all analyses in the study.

**Inclusion and exclusion criteria**

The participants in the study met specific inclusion criteria. Inclusion criteria included those participants who identified themselves as family caregivers. They must be 18 years of age or older, and provided care for an adult (18 years of age or older) diagnosed with a chronic disease. Family caregivers must provide care to persons who needed assistance in a minimum of 2 activities for at least one month and for which the care recipient was previously independent. These activities may be either identified as an ADL and/or IADL. Participants also were asked about complex clinical tasks they may also perform. However, it was not required that they assist with these tasks to participate in the study. Participants must have been able to comprehend enough English so that they could understand the benefits and risks associated with the study, provided consent to participate in the study, and completed the study instruments. Participants were excluded if they identified themselves as caregivers of those with acute illnesses and care provided was anticipated for a short, limited period of time less than 1 month.

**Procedures**

A convenience sampling strategy was used to find caregivers who provided care to a family member with a chronic illness. Selected organizations that supported family caregivers assisted in contacting family caregivers for the study. This strategy was also used to find a varied pool of caregivers who experienced differing levels of stress while caring for care recipients who have differing levels of need as a result of their illness trajectory. Due to the differing needs of caregivers, two methods of data collection were used. Study survey instruments were provided primarily through a web based survey tool called Qualtrics, or by paper instruments when potential study participants specifically

requested this as an alternative to the web based survey tool. Survey questionnaires were constructed similarly whether web or paper based.

### **Recruitment**

Family caregivers were recruited to participate in the study through use of the selected organization client lists. They were initially recruited by either organization employees, email, mail or a combination. A recruitment flyer provided by employees and/or an email letter outlined the study goals and procedures for completion of study instruments via a web based survey. An additional snowball strategy was added to increase family caregiver recruitment for caregivers difficult to reach. A link to the survey was provided for easy access. If a potential participant expressed interest; but was unable to complete the web based survey a paper instrument with a postage paid pre addressed return envelope was provided. Limitations of this recruitment method related to participant bias are acknowledged in that differences may exist in participants recruited through employee contact and those that were contacted only through email in their ability to participate in the web based survey or paper instruments.

### **Data collection procedures**

Family caregivers were contacted initially through organizations by email or mail. A letter outlining the purposes of the study, anonymity of responses, and how to contact the researcher was provided. Additionally, a link to the survey was provided in the initial email study letter. The primary survey mode consisted of a web based survey that was self-administered. However, if the subject expressed interest to the employee or researcher to participate in the study, but is unable with the web based survey, a paper instrument was provided. Contact information for the researcher was provided if

questions related to the study arose. Once the survey was accessed, information related to consent was provided and once the participant agreed to the consent, they progressed to the survey. A series of preliminary screening questions were asked at the beginning of the survey to address inclusion criteria. Screening questions included

1. In the past 12 months, have you provided unpaid care or assistance to a relative, partner or friend who was 18 years or older?
2. Has the assistance or care you provide or provided lasted more than one month?
3. Have you provided assistance to the care recipient in a least 2 of the following activities during the last 12 months: bathing, dressing, toileting, transferring, continence, feeding, use of telephone, shopping, food preparation, housekeeping, laundry, transportation, medication management, or financial assistance?

If the potential study participant answered “yes” to the screening questions, inclusion criteria were met and the survey continued. If the potential study participant answered “no” to any of the above questions, the potential study participant did not meet the inclusion criteria and the survey ended prior to study instruments being completed with a” thank you for their interest”. In aggregate, study participants are expected to take 15 minutes to complete study survey questionnaires.

## **Measures**

**Background context factors.** Background context factors of the family caregiver including age, gender, ethnicity, employment status, education level, relationship to the care recipient, income and length of time caregiving were collected from all participants (Appendix A). Demographic categories were consistent with Reinhard et al. (2012) study



with the exception of race/ethnicity and educational attainment. Both of these categories were based on the 2013 US Bureau of Labor Statistics.

**Age.** Family caregivers were asked to report their age on their last birthday.

**Gender.** Gender was collected based on the family caregiver's report of male or female.

**Race and Ethnicity.** Race and ethnicity categories were collected based on the US Bureau of Labor statistics report (2013) on labor characteristics. Categories included white, black or African American, Asian, American Indian or Alaska Native, Native Hawaiian or Pacific Islander, two or more races, Hispanic or Latino.

**Employment status.** Employment categories used consisted of full time, part time, not working, retired, and disabled. If employed full or part time, participants were asked to report how many hours per week they worked.

**Education level.** Education categories used included less than high school, high school, some college or associates degree, bachelor's degree, and advanced degrees. These categories were obtained from the US Bureau of Labor Statistics (2013) report on wage earnings.

**Caregiver Relationship.** The family caregiver reported what their relationship was to the care recipient. Categories included spouse or partner, child, other family member, and friend or neighbor.

**Income.** Income categories used included less than 15,000; 15,000 to 29,000, 30,000 to 49,000; 50,000 to 74,999; 75,000 to 99,999; 100,000 or more.

**Length of time caregiving.** Length of time caregiving was measured according to months and/or years.

**Care recipient diagnosis.** In an effort to assess the chronic nature of the care recipient's diagnosis, data were collected on physical health of the care recipient. Categories included stroke or hypertension, musculoskeletal (arthritis, osteoporosis, etc.), cardiac disease (heart attack, angina, congestive heart failure, etc.), diabetes, cancer, lung disease, kidney disease, movement disorder (Parkinsons, etc.), trauma, neurological disorders (ALS, epilepsy, Epstein Barr, etc.), congenital conditions (CP, autism, Downs, etc.), traumatic brain injury, gastro-intestinal problems, paralysis, multiple sclerosis, transplant (kidney, liver, stem cell), HIV/AIDS, memory problems, including dementia or Alzheimer's, depression or mental illness.

**Caregiving demands.** Caregiving demands were measured as identified by standard ADL and IADL categories. Additional questions related to the assistance with complex clinical tasks were also asked (Appendix B).

**ADL.** ADLs were measured using six categories established by Katz et al. (1963) Index of ADL scale including bathing, dressing, toileting, transfer, continence, and feeding. Participants selected all ADLs that required the caregiver's assistance.

**IADL.** IADLs were measured using the eight categories established by the Lawton-Brody Instrumental Activities of Daily Living scale (Lawton & Brody, 1969) including use of the telephone, shopping, food preparation, housekeeping, laundry, transportation, medication management, and finances. Participants selected all IADLs that required the caregiver's assistance.

**Clinical tasks.** Complex clinical tasks included activities that caregivers performed for the care recipient that are similar to what nurses would provide in an acute care or long term care setting. Reinhard et al. (2012) surveyed caregivers and found that

the activities often provided included incontinence care, wound care, dietary supplementation, and medication management often including both intravenous and injectable medications. Complex clinical tasks for this study were identified as those categories of clinical tasks previously surveyed by Reinhard et al. (2012). Participants selected all complex clinical tasks that required the caregiver's assistance.

**Coping and Social Support.** The variables of coping and social support were measured using the Brief COPE (Coping Orientations to Problems Experienced) scale (Appendix C). The Brief COPE scale is a 28 item scale that consists of 14 subscales that measure various dimensions of coping including active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. Each subscale contains 2 distinct items that measure the specific dimension of coping identified. It is an abbreviation of the full COPE inventory which consists of 60 items. The scale was abbreviated due to the original scale being considered redundant and difficult to complete due to its length by participants. The instrument uses a 4 point Likert scale with 1 stating "I haven't been doing this at all" to 4 stating "I've been doing this a lot." The Brief COPE was tested with 168 participants three times over a one year time frame. Reliability of the 14 subscales ranged with alpha coefficients ranging 0.50 (venting) to 0.90 (substance use). Of the 14 subscales, 6 had alpha coefficients greater than 0.70 and 11 of the scales were 0.64 or greater. When specifically assessing social support, the instrument has two subscales; one assessing use of emotional support ( $\alpha = 0.71$ ) and the other measuring use of instrumental support ( $\alpha = 0.64$ ) (Carver, 1997).

Carver (1997) indicated that the instrument does not need to be used in its entirety; selected subscales can be used individually for specific consideration in research.

Researchers (Coolidge, Segal, Hook, & Stewart, 2000; Cooper, Katona, & Livingston, 2008) have conceptualized the 14 subscales of the Brief COPE according to factor structure into 3 main groupings of coping; emotion focused strategies, problem focused strategies, and dysfunctional coping strategies. Although Carver et al. (1989) discussed the theoretical underpinnings of the scale in relation to these groupings; the authors constructed the scale using the 14 subscales of coping dimensions and did not validate the scale using these groupings. Of interest to this study, Cooper et al. (2008) studied family caregivers of dementia patients over time and reported reliability of the 3 groupings as 0.72 for the emotion focused grouping, 0.84 for the problem focused grouping and 0.75 for the dysfunctional coping scale. They deemed test retest as adequate for the emotion focused, problem focused and dysfunctional focused grouping as  $r = 0.58$ ,  $r = 0.72$ , and  $r = 0.68$ ,  $p < 0.01$ .

Therefore, although researchers have combined the subscales into dimensional groupings for the Brief COPE, the variable of coping was measured according to the original construction of the Brief COPE subscales. Social support was measured using the 2 subscales Carver (1997) identified as use of emotional and instrumental support.

**Caregiver burden.** Caregiver burden was measured using the Zarit Burden Interview (ZBI) (Appendix D). It is a commonly used caregiver burden instrument in caregiver research. The 22 item scale can be self-administered or administered during an interview. Scoring ranges from 0 - 4 with higher ratings indicating greater caregiver burden (Knight, Fox, & Chou, 2000). Knight, Fox, and Chou (2000) reported reliability

with Cronbach's alpha as 0.88 and 0.91 with test retest reliability reported at 0.71. Additionally, the instrument was used in a factor analysis study with two samples and reported reliability in their sample at 0.92 (Knight et al., 2000). Further reliability and validity was reported in a study of instrument review examining caregiver burden in heart failure patients. ZBI reliability was reported in this review as 0.91 with test retest reliability of 0.71. Validity was established based on extensive content and construct testing (Harkness & Tranmer, 2007).

**Compassion fatigue and compassion satisfaction.** Compassion fatigue and compassion satisfaction were measured using the Professional Quality of Life scale (ProQOL) (Appendix E). The ProQOL scale is a revised version of the original Compassion Fatigue Self Test. The scale was originally developed by Charles Figley in the early 1980's and then revised by Figley and Beth Stamm in 1988. Stamm continued with the development and the scale was renamed the ProQOL (Stamm, 2010). Stamm (2010) reported good construct validity with over 200 published papers; with 100 published research papers. Of the 100 research studies, over half used the ProQOL or an earlier version.

The scale consists of three subscales; compassion satisfaction, burnout, and secondary traumatic stress. Stamm (2010) described that compassion fatigue consists of two components; burnout and secondary traumatic stress. Stamm (2010) reported that the subscale of compassion satisfaction had a reliability of 0.88, with the burnout subscale as 0.75 and secondary traumatic stress subscale as 0.81. Additionally, Bride, Radey, and Figley (2007) reported the scale subscales reliability ranges from 0.86 – 0.94 in studies with professional caregivers. Although no composite score exists for the entire scale,

each subscale has defined cut scores that contribute to identifying high, average/moderate, or low levels of compassion satisfaction, burnout, and secondary traumatic stress. Multiple combinations of scale scores offer distinct characteristics for interpretation. For example, high compassion satisfaction with low levels of burnout and secondary traumatic stress is the most positive result indicating that caregiving contributes to positive reinforcement from their work. High levels of burnout with moderate to low levels of compassion satisfaction and secondary traumatic stress are at higher risk for feeling there is nothing that can be done to help the situation. They often are disengaged and feel they are ineffective. High levels of secondary traumatic stress with moderate to low levels of burnout and compassion satisfaction indicate that persons are often overwhelmed by the experience and are characterized by feelings of fear. High levels of secondary traumatic stress and high levels of compassion satisfaction with low levels of burnout are unique and usually are indicative of highly stressful environments in which the person feels extreme fear, however, feel their work matters. Finally, high levels of secondary traumatic stress and burnout with low levels of compassion satisfaction is the most distressing combination. With this combination, persons feel not only overwhelmed and useless, but also experience fear within the situation (Stamm, 2010).

### **Statistical Analyses**

**Data management.** Once subjects completed the survey, results were collected in Qualtrics. Access to the survey and survey results was password protected in which only the researcher had access to the login and password. Results were screened within Qualtrics to determine the number of total completed surveys. Anonymity was assured as no names or email addresses are associated with the survey. A cookie was used to ensure

that a participant only completed the survey once. To additionally assure anonymity, there was no ability to determine if participants who completed the paper survey also completed the web survey. This was accepted as a potential limitation. Once the desired number of subjects responded to the survey, results were exported to SPSS. For those subjects who completed a paper survey, data were coded and entered into the data set. Data entry was double checked for accuracy. Data files were contained on a secure server in which only the researcher had access.

**Data analysis.** Data analysis was completed using SPSS. Variables were defined and named to create the data file in SPSS. Data from Qualtrics was directly imported into SPSS. Data from paper surveys were entered and double checked for accuracy. Data files were examined and screened for errors and missing data. Missing data were analyzed for determination of extent, patterns, and reasons for incomplete cases. For missing variable data on demographic variables, analysis occurred using the “exclude cases pairwise” option so that all cases were included unless the data was missing for a particular analysis. Normality of the data was assessed by examining skewness, kurtosis, tests of normality such as Kolmogorov-Smirnov (K-S) statistic, histograms, QQ plots and box and whiskers plots. If data were not deemed normal, nonparametric alternatives were considered. Reliability of the scales used in the study were conducted, assessed, and compared to previous reported results (Pallant, 2013).

**Statistical analyses.** Descriptive statistics related to background context factors were collected and analyzed to describe the participants in this study. Frequencies were used to assess the categorical variables. Descriptive statistics of mean, median and standard deviation were used to describe continuous variables.

Research question one was answered using the ProQOL instrument, with higher scores on the burnout and secondary traumatic stress subscales indicating higher levels of compassion fatigue. Levels of compassion satisfaction were also determined and in addition to the other two scales were used to interpret scores. Additionally, predetermined cut scores based on average scores with scores set at the 25<sup>th</sup> and 75<sup>th</sup> percentiles were used to identify whether participants exhibited a low, average/moderate, or high level of compassion fatigue and compassion satisfaction (Stamm, 2010).

Research question two was answered with Pearson's correlation. If assumptions were not met, the nonparametric alternative of Spearman's Rank Order Correlation was used. The relationship between caregiver burden and compassion fatigue has not been determined. Therefore, the relationship between caregiver burden with compassion satisfaction, burnout, and secondary traumatic stress was assessed and described the overall relationship between caregiver burden and compassion fatigue. To determine if a violation of assumptions had occurred, a scatterplot was analyzed to check for normality, linearity and homoscedasticity. In this analysis, outliers and shape were evaluated to determine whether the points were outside the range of other points which can negatively influence the analysis. Determination of whether the points are somewhat straight, narrow, and cigar shaped indicated a strong correlation. This shape can also tell whether the relationship was positive or negative. A positive relationship moves upward; whereas, a negative relationship moves downward. The direction can also be determined by whether the correlation numeric value was positive or negative between the two variables. The strength of the relationship was determined by assessing the value. The possible range of values is -1 to +1. Guidelines to interpret the values were as follows; a



small correlation was 0.10 to 0.29; medium correlation was 0.30 to 0.49; and a large correlation was 0.50 to 1.0. Additionally, a coefficient of determination between the variables was calculated by squaring the  $r$  value to determine the variables shared variance. The significance level with a correlation indicated how much confidence there were in the results (Pallant, 2013).

Research question three used t-tests and one way analysis of variance (ANOVA) with post hoc tests to determine if differences existed in compassion fatigue scores based on the specific background context factor. Nonparametric alternatives of Mann-Whitney U test and Kruskal-Wallis test were used when assumptions were not met. General assumptions for parametric tests comparing groups such as t-tests and ANOVA included level of measurement, random sampling, independence of observations, normal distribution, and homogeneity of variance. As recommended, the level of measurement of the dependent variable (compassion fatigue) was continuous. Due to convenience sampling, awareness of violating the assumption of random sampling is common and therefore weakens the generalizability of the results. Independence of observations was assured as each participant independently completed the measurement tools. Normal distributions were checked using skew, kurtosis, QQ plots, box and whiskers plots, and histograms to visualize the distribution. The Kolmogorov-Smirnov (K-S) statistic was used to assess normality. A non-significant value (greater than .05) indicated a normal distribution. Finally, homogeneity of variance was tested to assess for equal variances.

Evaluation of the t-test result is dependent on the Levene's test. For the t-test, if the Levene's test significance level was larger than .05, no violation occurred and equal variances are assumed. If a violation occurred, an alternative t-test value was used

assuming variances were not equal. When the variances were equal, the reported result was the t value listed in the “equal variances assumed” row. The significance level, less than .05, was determined by the researcher. Therefore, group differences existed if the t-test value was significant. In order to determine whether the difference found was meaningful, an effect size was calculated. An eta squared value represented the effect size and was manually calculated using a formula;  $t^2$  divided by  $t^2 + (N1 + N2 - 2)$ . This value, as a percentage, reflected how much difference in compassion fatigue scores was explained by the variable (Pallant, 2013).

ANOVA tests were evaluated to determine whether there was a significant difference between the identified groups and then, if significant, post hoc tests determined which groups were different. In the output, the descriptives table provided information related to each group related to number, means, standard deviations, minimum and maximum values. Once this table was checked and verified, the Levene’s test for homogeneity of variances was assessed. The Levene’s test was not violated if the significance value was greater than 0.05. If the assumption was violated, the Robust Tests of Equality of Means was used that consist of the Welch and Brown-Forsythe tests. The ANOVA table provided both between groups and within groups sum of squares and degrees of freedom. If the value was significant at less than or equal to 0.05, then there was a difference in the dependent variable scores between the groups. To find which groups were significantly different from each other, the mean difference column in the Multiple Comparisons table was evaluated. Any groups with an asterik indicated that the groups compared were different. The significance column indicated the exact level of significance at or less than 0.05. An effect size was calculated using the eta squared value

by dividing the sum of squares between groups by the total sum of squares. The value has importance in determining whether a statistically significant result was practically important (Pallant, 2013).

Research questions four and five were answered using multiple regression to determine the variance explained in the dependent variables (compassion fatigue and compassion satisfaction) by the independent variables or predictors (Pallant, 2013). Hierarchical multiple regression assessed how well independent variables predicted the outcome of compassion fatigue and compassion satisfaction in family caregivers. In this test, all independent (predictor) variables were entered into the equation in 2 blocks based on whether the variables were fixed such as age or gender, or variable, such as burden and ADLs. The results revealed how much of the variance in the dependent variables were explained by the independent variables. Assumptions of multiple regression included sample size, multicollinearity, outliers, normality, linearity, and homoscedasticity. Each were evaluated prior to analysis. Sample size impacts the generalizability of the results. As discussed in the power analysis, one common sample size estimate in multiple regression was that 15 participants were needed for each predictor variable (Pallant, 2013).

Multicollinearity is not advised in multiple regression. Tests used to assess for multicollinearity included correlations between variables and tolerance and VIF values. Independent variables should have some correlation (greater than .3) to the dependent variable, however, should not be too highly correlated with each other. If high correlations between the independent variables were found (greater than .7), removing one of the variables from the analysis was considered. Tolerance and VIF values are

found on the the coefficient table and are inversely related. Values of tolerance that were very small (less than .10) and VIF values (greater than 10) indicated multiple correlation with the other variables and suggested multicollinearity. Normality, homoscedascity, and outliers were assessed by graphs including the normal probability plots and scatterplots (Pallant, 2013).

In the multiple regression model, the R Square and the Adjusted R Square were evaluated. The R Square told how much variance in compassion fatigue scores was explained by the model. The Adjusted R Square, a corrected value, was also evaluated. To compare the independent variables contribution to the explained variance, the standardized beta coefficient value was reported. The independent variable with the largest value, made the largest unique contribution to the model. The significance level (less than .05) indicated that the independent variable made a statistically significant unique contribution to the model. To further analyze significant independent variables in the model, the Part correlation value was squared. This value indicated how much each specific independent variable contributed to the total variance and thus how much the total R Square would decrease if the variable was not included in the model (Pallant, 2013).

### **Human subjects' protection**

Participants recruited included adults who self identify as serving a primary caregiving role and were considered regardless of gender, age, or race. Participants have already accessed community services for family caregivers through affiliation with the community organization and thus have access to support services. The risk of harm to subjects in this study was minimal because the survey was anonymous and participant

answers were not associated with email addresses. This study applied for an expedited review due to minimal risk of harm (UNM, n.d.). Human research protection approvals were obtained from the University of New Mexico and the University of North Carolina Charlotte.

## **Chapter Four: Results**

### **Introduction**

The purpose of this study was to examine the concept of compassion fatigue and compassion satisfaction among family caregivers using a cross sectional descriptive survey design with a convenience sample. A second purpose was to explore the relationship between caregiver burden and compassion fatigue and to determine which characteristics were predictive for the level of compassion fatigue in primary family caregivers for care recipients with chronic illness. This chapter presents the study results including descriptive statistics of study variables, demographics of the sample, and analyses of research questions. All analyses were conducted using SPSS 21.0 for Windows to evaluate all assumptions, scale reliability, and to derive the findings.

### **Data Preparation**

Data from the web based survey tool Qualtrics was directly exported to SPSS for analysis. Additional cases that were mailed ( $n = 5$ ) to the researcher were added to the data file. Data were then screened to determine the total number of respondents ( $n = 278$ ), those who provided consent ( $n = 272$ ), those who met inclusionary criteria ( $n = 209$ ), those who completed the survey ( $n = 176$ ) and the number of cases with missing data ( $n = 66$ ). Then, cases with missing data were evaluated to determine the extent and type of data missing. This evaluation determined whether the case should be deleted or retained in the data file. If retained, the decision related to the technique of handling such missing data was identified.

Missing data are known to cause issues related to decreased sample size and decreased statistical power. However, determining whether listwise deletion is the best

method to handle missing data is questionable. The extent of missing data is one factor to consider and reported estimates from 10 – 40% of missing data on any variable have been suggested as determinates to delete a variable (Dodeen, 2003; El-Masri & Fox-Wasylyshyn, 2005; Newman, 2014; Schlomer, Bauman, & Card, 2010). In addition to the extent of missing data, the pattern of missing data, whether random or systematic, is considered another important factor. Techniques used to handle missing data include deletion and imputation techniques. Listwise deletion limits analysis to only those cases with complete data; which can drastically reduce sample size and power; resulting in bias. Thus, recommendations of using listwise deletion are limited to those which only result in a loss of 5-15% of cases (El-Masri & Fox-Wasylyshyn, 2005). Pairwise deletion uses data from cases for which the data for a particular analysis is complete; however, pairwise deletion complicates analysis due to differing sample sizes (El-Masri & Fox-Wasylyshyn, 2005; Newman, 2014; Schlomer, Bauman, & Card, 2010). Recommendations are to use pairwise deletion if the missing data does not exceed 20% (El-Masri & Fox-Wasylyshyn, 2005).

Imputation strategies involve using an estimate of the missing value to represent that missing value. Imputation techniques are viewed as better than deletion strategies since sample size and statistical power are retained. Case or person mean substitution replaces a missing value with the case mean of items of a particular measure. This option is used with psychometric measures or scales that are measuring a particular concept as it can be construed that items are correlated and thus mean scores of items completed is closely related and thus similar to other item scores. In a review of studies, case mean substitution is considered a robust method for psychometric measures if no more than

30% of items are missing (El-Masri & Fox-Wasylyshyn, 2005). Specifically, Hawthorne and Elliott (2005) found that person case mean substitution was a preferred method with scales where half the items were present. Advantages include ease of calculation and the use of all available data. This method has limited application when single variables are used or when all items in a scale are missing. In addition, Dodeen (2003) also found that valid mean substitution was similar but preferred over multiple regression replacement when missing data were 10%, 30% and 50% in Likert type scales. In this study, 20% missing data was used as a conservative estimate to use mean substitution. Finally, Newton (2014) stated that when a participant responds to any number of items on a multi-item scale, the average score should be used as a replacement for missing items on that scale. The author also recommended that person mean substitution is preferable over listwise deletion due to theoretical, ethical and statistical reasons.

Additional single imputation strategies include sample mean substitution and regression imputation. Sample mean substitution is one of the most commonly used methods and it uses the sample mean to replace the missing value. It assumes that the sample mean is the best guess for a variable that is normally distributed. If the variable is not normally distributed, the median is considered the best estimate. Although an overall conservative approach, issues related to true estimates and bias are noted, therefore, sample mean should be used when data are missing completely at random and the extent of missingness is very small (El-Masri & Fox-Wasylyshyn, 2005). Regression based imputation uses other variables to predict responses for missing data on a given variable. This strategy provides a methodical approach for determining an estimate for missing



data. However, it can lead to over prediction if the missing data were increased due to multicollinearity (El-Masri & Fox-Wasylyshyn, 2005).

Multiple imputation is a multi-step process where multiple sets of data are created through a probability model and each data set is analyzed separately and the results of all data are pooled to provide one result. The advantage of this method is that it provides uncertainty about the values of missing data and handles violations of non-normality. However, even though Newman (2014) recommended multiple imputation over deletion methods for item level missing data if missing data are over 10%, the author acknowledged this cutoff is arbitrary. It is also suggested that multiple imputation is suitable for item and variable missing data; however, it is often not feasible for a researcher to use due to complex methodology, time intensiveness, and lack of availability on statistical software packages (Fox-Wasylyshyn & El-Masri, 2005).

Based on data obtained, missing data for this study included a combination of methods including listwise deletion, pairwise deletion and person case mean substitution. For participants that failed to complete the survey that resulted in attrition, those cases were deleted from analysis. In a total of 278 participants who started the survey, 176 cases completed the survey. A conservative approach will be used in that if more than 20% of items were missing from any one scale, those cases will be deleted ( $n = 8$ ). Across instruments, cases noted with missing data on the Brief COPE were 10% and Zarit Burden inventory was 4%. The ProQOL instrument had the highest percentage (26%) of cases with missing data; however, the majority of cases only had one item missing (57%). As a result, for cases with missing data on any instrument that did not extend beyond 20%, the person case mean was used as the substitution. Additional

missing data on demographic and other variables were small and therefore pairwise deletion was used. After analysis, the final number of participants for the study was  $n = 168$ .

### **Demographics**

The demographic characteristics of the total sample are presented in Table 1 and characteristics regarding the caregiving experience are presented in Table 2. Overall, family caregivers who participated in the study were predominantly female ( $n = 121$ , 72%), White ( $n = 130$ , 77%) with an age range of 19 – 87 years ( $M = 57.94$ ,  $SD = 14.3$ ). The majority of participants were educated with at least some college ( $n = 145$ , 90%) with an income level of at least \$30,000 ( $n = 108$ , 67%). Family caregivers described their caregiving experience regarding length of time caregiving having ranged from 1- 25 years ( $M = 7.04$ ,  $SD = 5.42$ ) with an average of 50 hours per week spent caregiving. Most of the sample were spouses ( $n = 84$ , 50%), characterized their own health as good ( $n = 100$ , 59.5%) and identified their caregiving experiences as resulting in both positive and negative feelings ( $n = 145$ , 86.3%). Participants were recruited from organizations that provided some level of support for caregivers and care recipients. Organizations were identified as such by participants are presented in Table 3. Participants indicated that the majority of the sample received hospice and palliative care ( $n = 62$ , 36.9%). Additionally, 17.9% ( $n = 30$ ) of participants reported receiving support from other organizations and 23.2% ( $n = 39$ ) reported receiving no organizational support.

**Table 1**  
*Caregiver Demographics*

Characteristic	Family Caregiver (n=168)	
	M	SD
Age	57.94	14.32
	n	%
<b>Gender</b>		
Male	42	25
Female	121	72
Not reported	5	3.0
<b>Ethnicity</b>		
White	130	77.4
Black or African American	22	13.1
Asian	1	.6
Two or more races	5	3.0
Prefer not to report	2	1.2
Not reported	3	3
<b>Education</b>		
High School	16	9.5
Some college or associates degree	53	31.5
Bachelors	43	25.6
Advanced degree	49	29.2
Not reported	7	4.2
<b>Income</b>		
Less than \$15,000	7	4.2
\$15,000-\$29,999	23	13.7
\$30,000-49,999	26	15.5
\$50,000-\$74,999	32	19.0
\$75,000-\$99,999	18	10.7
\$100,000 or more	32	19.0
Prefer not to report	24	14.3
Not reported	6	3.6
<b>Employment</b>		
Full time	59	36.2
Part time	23	13.7
Not working	16	9.5
Retired	63	37.5
Disabled	2	1.2
Not reported	5	3.0
<b>Relationship to Care Recipient</b>		
Spouse	84	50
Child	35	20.8
Other Family Member	47	28
Friend or Neighbor	2	1.2

**Table 2**  
*Caregiving Experience Characteristics*

Characteristic	Family Caregiver (n=168)	
	M (Range)	SD
Years Caregiving	7.04 (1-25)	5.42
Hours per Week Caregiving	50.32 (1-168)	53.62
	n	%
Feelings Experienced Caregiving		
Positive	19	11.3
Negative	4	2.4
Both Positive and Negative	145	86.3
Description of Own Health		
Excellent	38	22.6
Good	100	59.5
Fair	24	14.3
Poor	6	3.6
Major Health Issues for Caregiver		
None	65	38.7
M-S (Arthritis, Osteoporosis)	35	20.8
Depression	23	13.7
Diabetes	22	13.1
Stroke/HTN	21	12.5

**Table 3**  
*Organizations Identified by Participants as Providing Support*

Organization	Family Caregiver (n=168)	
	n	%
Hospice & Palliative Care	62	36.9
Family Caregiver Support Programs	24	14.3
ALS Association	18	10.7
Multiple Sclerosis Society	29	17.3
Other	30	17.9
None	39	23.2

## Descriptive Statistics

### Study Variables

**Caregiving Demands.** Participants were asked to select which of the following activities that they assisted their family member. Activities were categorized into three categories; activities of daily living (ADL), instrumental activities of daily living (IADL), and complex clinical tasks. Then a total number of caregiving tasks variable was created. Of the 22 items, six items were characterized as ADLs with eight items in each of the other categories, IADLs and complex clinical tasks. Findings revealed that the majority of caregivers performed three to four ADLs ( $n = 127, 75.6\%$ ), five to six IADLs ( $n = 103, 61.3\%$ ), and zero to two complex clinical tasks ( $n = 96, 57.1\%$ ). In total, the majority provided ten or less tasks for their family member ( $n = 90, 55.6\%$ ), with close to 25% providing 15 or more tasks.

**Social support & Coping.** Reported reliability of the Brief COPE 14 subscales ranged with alpha coefficients ranging 0.50 (venting) to 0.90 (substance use). Subscales used to measure social support included one assessing use of emotional support ( $\alpha=0.71$ ) and the other assessing the use of instrumental support ( $\alpha = 0.64$ ) (Carver, 1997). In this study, the total instrument had a Cronbach alpha of 0.825, with subscales ranging from 0.56 (self-blame) to 0.96 (substance use). Overall, nine of the 14 subscales had Cronbach alpha scores above 0.70, with the subscales of emotional support ( $\alpha = 0.82$ ) and instrumental support ( $\alpha = 0.81$ ) performing better than reported reliability.

**Caregiver burden.** Caregiver burden was measured using the Zarit Caregiver Burden Interview (ZBI). The frequency table was reviewed to ensure accuracy of data and the range of scores are noted from 2 to 66, with a mean of 32.495. The measures of

central tendency, dispersion, and distribution are summarized in Table 4. The K-S score is non-significant at 0.200 indicating a normal distribution.

**Table 4**

*Summary Central Tendency & Distribution of ZBI and ProQOL*

Variable	Central Tendency		Dispersion		Distribution		Tests of Normality		
	Mean	Median	SD	Variance	Skew	Kurtosis	KS	df	Sig
ZBI	32.46	32.00	13.89	192.98	.232	-.319	.055	168	.148
ProQOL									
CS	34.18	34.00	7.30	53.36	-.123	-.243	.056	168	.200
BO	24.47	24.00	6.42	41.34	.130	-.548	.058	168	.200
STS	22.16	22.15	6.94	48.14	.238	-.616	.081	168	.009
SqRT STS	4.65	4.71	.75	.56	-.064	-.755	.073	168	.031

Reliability of the ZBI was reported by Knight, Fox, and Chou (2000) to have a Cronbach's alpha as 0.88 and 0.91 with test retest reliability reported at 0.71.

Additionally, the instrument was used in a factor analysis study with two samples and reported reliability in their sample at 0.92 (Knight et al., 2000). In this study, the Cronbach alpha coefficient was 0.89 which compares similarly.

Scoring of the ZBI is easily calculated by summing the total score on all items with no reversal of items required. Possible scores on the instrument range from 0 to 88. Higher scores on the instrument indicate higher levels of burden. Hebert, Bravo, and Preville (2000) reported that score ranges of 0 to 8 indicated low burden, with scores of 9 to 17 represented moderate burden, 18 to 32 indicated high burden and over 33 severe burden. In addition, Schreiner, Morimoto, Arai, and Zarit (2006) identified a cut off score of 25 on the instrument, indicating that those with scores of 25 or less had low burden and those with scores greater than 25 had high burden and needed additional assessment and intervention. Using these assessment parameters, according to Hebert et al. (2000)

cut points, 83% reported high or severe levels of burden. Similarly, when using Schreniner et al. (2006) cut points, 71% reported high levels of burden indicating a need for further evaluation.

**Compassion satisfaction & Compassion fatigue.** Compassion satisfaction and compassion fatigue were measured using the Professional Quality of Life scale (ProQOL) version 5. The measures of central tendency, dispersion, and distribution are summarized in Table 4. For the compassion satisfaction and burnout subscales, the K-S scores are both non-significant at 0.200 indicating normal distributions. However, the K-S score on the secondary traumatic stress subscale was significant at 0.009 indicating a non-normal distribution. A square root transformation was conducted that resulted in a K-S of 0.031, with normal skew and kurtosis scores, with histogram and QQ plots appearing normal. Therefore, the distribution was considered normal.

Each subscale, demonstrated good reliability with a Cronbach alpha coefficient of 0.90 on the compassion satisfaction subscale, 0.78 on the burnout subscale and 0.82 on the secondary traumatic stress subscale. These compare similarly to Stamm's (2010) reported reliability of compassion satisfaction subscale as 0.88, the burnout subscale as 0.75 and secondary traumatic stress subscale as 0.81. Each subscale is comprised of 10 items, with a total possible score on each subscale of 50 (Stamm, 2010).

### **Analysis of Data**

Descriptive and inferential statistics were used to investigate the five research questions.

1. What is the level of compassion fatigue and compassion satisfaction in family caregivers?

2. What is the relationship between caregiver burden and compassion fatigue?
3. Do background context factors (age, gender, ethnicity, employment status, caregiver education, caregiver relationship, income) contribute to differences in compassion fatigue scores?
4. Do caregiving demands, length of time caregiving, social support, coping, and caregiver burden contribute to the prediction of compassion fatigue in family caregivers?
5. Do caregiving demands, length of time caregiving, social support, coping and caregiver burden contribute to compassion satisfaction in family caregivers?

### **Research Question One**

To answer the first research question, what is the level of compassion fatigue and compassion satisfaction in family caregivers, the Professional Quality of Life scale (ProQOL) version 5 was used. The scale is comprised of three subscales; compassion satisfaction, burnout and secondary traumatic stress. The concept of compassion fatigue is represented by the subscales of burnout and secondary traumatic stress. The instrument asked subjects to rate on a scale of 1 to 5 how often the participant experienced items in the last 30 days with 1 representing “never” and 5 representing “very often”. Raw scores on each subscale were totaled according to Stamm (2010) with cut scores identified. Compassion satisfaction scores of 22 or less indicated low levels, score ranges of 22 – 42 indicated average levels, and score ranges of 43 and higher indicated high levels of compassion satisfaction. For the burnout and secondary traumatic subscales, scores of 22 or less indicated low levels, 22-41 indicated average levels and 42 and higher indicated high levels of compassion fatigue (Stamm, 2010).



A summary of results on the instrument are reported in Table 5. The majority of the sample, had average level of compassion satisfaction (n = 139, 82.7%) with average levels of compassion fatigue, represented by the burnout (n = 100, 59.5%) and secondary traumatic stress subscales (n = 84, 50%). It is important to note that very few participants scored low on compassion satisfaction (n = 5, 3%) and no participant scored high on burnout or secondary traumatic distress.

**Table 5**  
ProQOL Results

Subscale	M(SD)	95% Confidence Interval		Level	Frequency (n)	Percent (%)
		Lower	Upper			
CS	34.18(7.30)	33.07	35.29	Low ( $\leq 22$ )	5	3
				Average (23-42)	139	82.7
				High (43 + )	24	14.3
BO	24.47(6.43)	23.49	25.45	Low ( $\leq 22$ )	68	40.5
				Average (23-41)	100	59.5
				High (42 + )	0	0
STS	22.16(6.94)	21.10	23.21	Low ( $\leq 22$ )	84	50
				Average (23-41)	84	50
				High (42 + )	0	0

### Research Question Two

Research question two examined the relationship between caregiver burden as measured by the Zarit Caregiver Burden Interview and compassion fatigue as measured by the ProQOL instrument. To explore the relationships, a Pearson product-moment correlation coefficient was conducted. A summary of results are presented in Table 6. Preliminary analyses revealed no violation of assumptions of normality, linearity, and homoscedasticity. There was a strong positive relationship between caregiver burden and compassion fatigue as represented by burnout and secondary traumatic stress.

**Table 6***Pearson Product-moment Correlations between Caregiver burden and ProQOL subscales*

<b>Correlations</b>		burden total scale score	compassion satisfaction total score	burnout subscale total score	secondary traumatic stress subscale total score	transformed sq rt sts subscale
burden total scale score	Pearson	1	-.229**	.677**	.671**	.669**
	Correlation					
	Sig. (2-tailed)		.003	.000	.000	.000
	N	168	168	168	168	168
compassion satisfaction total score	Pearson	-.229**	1	-.443**	-.107	-.114
	Correlation					
	Sig. (2-tailed)	.003		.000	.166	.141
	N	168	168	168	168	168
burnout subscale total score	Pearson	.677**	-.443**	1	.709**	.711**
	Correlation					
	Sig. (2-tailed)	.000	.000		.000	.000
	N	168	168	168	168	168
secondary traumatic stress subscale total score	Pearson	.671**	-.107	.709**	1	.996**
	Correlation					
	Sig. (2-tailed)	.000	.166	.000		.000
	N	168	168	168	168	168
transformed sq rt sts subscale	Pearson	.669**	-.114	.711**	.996**	1
	Correlation					
	Sig. (2-tailed)	.000	.141	.000	.000	
	N	168	168	168	168	168

\*\*. Correlation is significant at the 0.01 level (2-tailed).

Results between caregiver burden and burnout showed that higher levels of caregiver burden were positively associated with higher levels of burnout,  $r = .677$ ,  $n = 168$ ,  $p < .000$ . The coefficient of determination was .458 indicating that 46% of the variance is shared by the two variables. Similar results were found between caregiver burden and secondary traumatic stress,  $r = .669$ ,  $n = 168$ ,  $p < .000$  with the coefficient of determination of .447 or 45% shared variance. In addition, a small negative association was found between caregiver burden and compassion satisfaction,  $r = -.229$ ,  $n = 168$ ,  $p < .003$  with a 5% shared variance. However, when assessing the correlation between the subscales of compassion satisfaction and burnout, the negative relationship was stronger,  $r = -.443$ ,  $n = 168$ ,  $p < .000$ .

Using the cut scores identified by Schreniner, Morimoto, Arai, and Zarit (2006) for low and high caregiver burden, an independent t-test was performed to determine whether there were differences in burnout, secondary traumatic stress and compassion satisfaction for caregiver burden. Group 1 comprised of those with low burden scores of 25 or less and group 2 were those with burden scores higher than 25. Equal variances were assumed based on non-significant Levene's test for all subscales and significant differences were found in relationship to all subscales of the ProQOL; compassion satisfaction, burnout and secondary traumatic stress. For burnout, Group 1 ( $M = 18.72$ ,  $SD = 4.33$ ) was significantly different from Group 2 ( $M = 26.77$ ,  $SD = 5.65$ ;  $t(166) = -.869$ ,  $p < .000$ , two tailed). The magnitude of the differences in the means (mean difference =  $-8.04$ , 95%  $CI$ :  $-9.84$  to  $-6.25$ ) was very large (eta squared = .321). Second, significant differences were found in relationship to secondary traumatic stress for Group

1 ( $M = 16.17$ ,  $SD = 4.63$ ) and Group 2 ( $M = 24.55$ ,  $SD = 6.23$ ;  $t(166) = -8.815$ ,  $p < .000$ , two tailed). The magnitude of the differences in the means (mean difference =  $-0.931$ , 95%  $CI$ :  $-1.139$  to  $-0.723$ ) was very large (eta squared =  $.318$ ). Finally in regards to compassion satisfaction, Group 1 ( $M = 36.48$ ,  $SD = 4.63$ ) differed from Group 2 ( $M = 33.25$ ,  $SD = 6.77$ ;  $t(166) = 2.63$ ,  $p = .009$ , two tailed). The magnitude of the differences in the means (mean difference =  $3.22$ , 95%  $CI$ :  $.806$  to  $5.65$ ) was small (eta squared =  $.04$ ). Results are presented in Table 7.

### **Research Question Three**

Research question three investigated whether background context factors (age, gender, ethnicity, employment status, caregiver education, caregiver relationship, income) contributed to differences in compassion fatigue scores. In the analyses conducted, significant results were found for gender, age, employment, and income. Independent sample t-tests were conducted to compare the scores on the ProQOL subscales with gender. Significant differences were found in relationship to burnout for males ( $M = 22.53$ ,  $SD = 7.13$ ) and females ( $M = 25.16$ ,  $SD = 5.99$ ;  $t(161) = -2.332$ ,  $p = .021$ , two tailed). The magnitude of the differences in the means (mean difference =  $-2.63$ , 95%  $CI$ :  $-4.86$  to  $-0.4035$ ) was small (eta squared =  $.03$ ). To explore this relationship further, a point biserial correlation was conducted. Even though small, a significant point biserial correlation was found between gender and burnout ( $r = .181$ ,  $n = 163$ ,  $p < .05$ ) and gender with secondary traumatic stress ( $r = .237$ ,  $n = 163$ ,  $p < .01$ ). Additionally, significant differences were found in relationship to secondary traumatic stress for males ( $M = 19.395$ ,  $SD = 6.68$ ) and females ( $M = 23.04$ ,  $SD = 6.73$ ;  $t(161) = -3.026$ ,  $p = .003$ ,

**Table 7**  
*Caregiver Burden Compared to ProQOL*

Group Statistics					
	burden	N	Mean	Std. Deviation	Std. Error Mean
compassion satisfaction	<= 25.00	48	36.4833	8.11721	1.17162
	25.01+	120	33.2563	6.77236	.61823
burnout	<= 25.00	48	18.7229	4.33115	.62515
	25.01+	120	26.7692	5.65320	.51606
secondary traumatic stress	<= 25.00	48	16.1688	4.63066	.66838
	25.01+	120	24.5500	6.23316	.56901

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
compassion satisfaction	Equal variances assumed	3.387	.068	2.632	166	.009	3.22708	1.22600	.80651	5.64765
burnout	Equal variances assumed	3.757	.054	-8.869	166	.000	-8.04625	.90726	-9.83751	-6.25499
sts	Equal variances assumed	4.295	.040	-8.426	166	.000	-8.38125	.99470	-10.34514	-6.41736
	Equal variances not assumed			-9.548	115.792	.000	-8.38125	.87778	-10.11984	-6.64266
Sts sq rt trsf	Equal variances assumed	.566	.453	-8.815	166	.000	-.931.31	.10565	-1.13990	-.72273

two tailed). The magnitude of the differences in the means (mean difference = -3.64, 95% *CI*: -6.02 to -1.27) was small (eta squared = .056).

Age was divided into 2 groups based on percentiles, Group 1 was less than 59 years and Group 2 was greater than 60 years. Significant differences were only found in compassion satisfaction subscale between Group 1 ( $M = 35.42$ ,  $SD = 7.54$ ) and Group 2 ( $M = 32.90$ ,  $SD = 6.71$ ;  $t(135) = -2.061$ ,  $p = .041$ , two tailed). The magnitude of the differences in the means (mean difference = 2.52, 95% *CI*: .101 to 4.93) was small (eta squared = .03).

A one way between-groups analysis of variance was conducted to explore the differences in ProQOL scores in ethnicity, employment status, caregiver education, caregiver relationship, and income. The only significant differences were found in employment and income. For employment, participants were divided into five groups according to employment status (Group 1: Full time; Group 2: Part time; Group 3: Not working, Group 4: Retired and Group 5: Disabled). There was a statistically significant difference at the  $p < .05$  level in burnout between the five groups:  $F(4, 158) = 2.76$ ,  $p = .03$ . The effect size was determined to be moderate by the eta squared = .065. However, the Tukey HSD post hoc tests were inconclusive and did not find a significant difference between any two groups. It is noted that Group 1 ( $M = 22.63$ ,  $SD = 5.96$ ) and Group 4 ( $M = 25.75$ ,  $SD = 6.76$ ) were close to significance at  $p = .051$ . For the secondary traumatic stress subscale there was a statistically significant difference between the five groups:  $F(4, 158) = 2.831$ ,  $p = .027$ . The effect size was determined to be moderate by the eta

squared = .067. However, the Tukey HSD post hoc tests did not find a significant difference between any two groups.

To explore the differences in ProQOL subscale scores with income a one way between-groups analysis of variance was conducted. For income, participants were divided into seven groups according to income (Group 1: Less than 15,000; Group 2: 15,000 to 29,999; Group 3: 30,000 to 49,999, Group 4: 50,000 to 74,999; Group 5: 75,000 to 99,999; Group 6: 100,000 or more; and Group 7: Prefer not to report). There was a statistically significant difference at the  $p < .05$  level in income between the seven groups for burnout:  $F(6, 155) = 2.55, p = .022$ . The effect size was determined to be moderate by the eta squared = .089. Post hoc comparisons using the Tukey HSD test indicated that Group 3 ( $M = 27.18, SD = 5.57$ ) was significantly different from Group 6 ( $M = 22.26, SD = 5.60$ ). For the secondary traumatic stress subscale, there was a statistically significant difference at the  $p < .05$  level in income between the seven groups:  $F(6, 155) = 2.344, p = .034$ . The effect size was determined to be moderate by the eta squared = .083. Post hoc comparisons using the Tukey HSD test did not indicate any groups that were significantly different from each other however, burnout and secondary traumatic stress was lower in higher income groups

#### **Research Question Four**

Hierarchical regression was used to assess whether caregiving demands, length of time caregiving, social support, coping, and caregiver burden contributed to the prediction of compassion fatigue in family caregivers after controlling for the influence of age, gender, and caregiver health. Caregiving demands were measured as the total

number of ADL, IADL, and complex clinical tasks performed. The length of time caregiving is represented by the number of hours per week spent caregiving. The Brief COPE scale measures coping through 14 subscales. Social support was measured using the two subscales of emotional and instrumental support. Coping patterns were measured using the remaining 12 subscales. To determine which coping subscales to enter in the regression, a correlation matrix was created to determine which coping subscales revealed a relationship with burnout and secondary traumatic stress. See Table 8 for the correlation matrix. Those that revealed a positive correlation ( $r > .30$ ) with both burnout and secondary traumatic stress were considered and entered into the regression. The coping pattern of denial yielded an  $r = .390$  with burnout and  $r = .330$  with secondary traumatic stress. The coping pattern of self-blame was positively associated with burnout ( $r = .401$ ) and secondary traumatic stress ( $r = .417$ ). Finally, the coping pattern of behavioral disengagement was positively associated with burnout ( $r = .446$ ) and secondary traumatic stress ( $r = .380$ ).

Regression analyses were conducted with both burnout and secondary traumatic stress subscales of the compassion fatigue instrument. Preliminary analyses were conducted to ensure no violation of assumptions of normality, linearity, multicollinearity, and homoscedasticity. Age, gender, and caregiver health were entered in Step 1 explaining 9% of the variance in burnout. After entering caregiving demands, length of time caregiving, social support, coping and caregiver burden at Step 2 the total variance explained by the model was 57.1%,  $F(11, 119) = 14.398$ ,  $p < .000$ . The predictors



**Table 8***Pearson Product-moment correlation between Brief COPE and ProQOL subscales*

Scale	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1. cs	—																		
2. bo	-.443**	—																	
3. sts	-.107	.709**	—																
4.sqrtsts	-.114	.711**	.996**	—															
5.self distraction	.045	.221**	.337**	.348**	—														
6. active coping	.238**	-.015	.163*	.159*	.218**	—													
7. denial	-.138	.390**	.347**	.330**	-.021	-.011	—												
8. subst.abuse	-.043	.224**	.209**	.204**	.053	-.022	.227**	—											
9. emotional support	.183*	-.004	.139	.138	.299**	.335**	.061	.109	—										
10. instrum. support	.135	.092	.197*	.186*	.279**	.391**	.070	-.034	.709**	—									
11. behavioral disengagement	-.287**	.381**	.381**	.380**	.152*	-.052	.343**	.188*	-.094	-.090	—								
12. venting	-.068	.276**	.260**	.262**	.248**	.203**	.185*	.201**	.417**	.406**	.198*	—							
13. positive reframing	.283**	-.171*	.047	.054	.239**	.374**	-.124	-.056	.196*	.160*	-.186*	.027	—						
14. planning	.079	.124	.328**	.325**	.172*	.610**	.136	-.041	.398**	.504**	.080	.334**	.318**	—					
15. humor	.190*	.065	.113	.117	.198*	.186*	.040	.034	.211**	.258**	.014	.245**	.245**	.264**	—				
16. acceptance	.235**	-.095	.048	.064	.312**	.275**	-.243**	-.099	.257**	.208**	-.154*	.103	.270**	.188*	.205**	—			
17. religion	.131	-.062	.192*	.198*	.000	.086	.113	-.169*	-.197*	.219**	-.055	-.016	.186*	.152*	-.065	.102	—		
18. self blame	-.158*	.401**	.421**	.417**	.240**	.141	.241**	.048	.031	.108	.435**	.274**	.055	.218**	.167*	.011	-.030	—	

explained an additional 48% of the variance after controlling for age, gender, and caregiver health,  $R$  square change = .481,  $F$  change (8, 119) = 16.682,  $p < .000$ . In the final model, two of the predictors were significant including caregiver burden (beta = .535,  $p < .000$ ) and the coping pattern of behavioral disengagement (beta = .175,  $p = .019$ ). The part correlation coefficient of caregiver burden was .418, uniquely explaining 17% of the variance. The part correlation coefficient of behavioral disengagement was .143, only explaining 2% of the variance. The model summary can be viewed in Table 9.

**Table 9**  
*Hierarchical Regression: Burnout*

**Model Summary<sup>c</sup>**

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.300 <sup>a</sup>	.090	.068	6.20629	.090	4.179	3	127	.007
2	.756 <sup>b</sup>	.571	.531	4.40189	.481	16.682	8	119	.000

- a. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?
- b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support
- c. Dependent Variable: burnout subscale total score

**ANOVA<sup>a</sup>**

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	482.948	3	160.983	4.179	.007 <sup>b</sup>
	Residual	4891.790	127	38.518		
	Total	5374.738	130			
2	Regression	3068.916	11	278.992	14.398	.000 <sup>c</sup>
	Residual	2305.822	119	19.377		
	Total	5374.738	130			

- a. Dependent Variable: burnout subscale total score
- b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?
- c. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support

A second regression analyses was conducted where age, gender, and caregiver health were entered in Step 1 explaining 17% of the variance in secondary traumatic stress. After entering caregiving demands, length of time caregiving, social support, coping and caregiver burden at Step 2 the total variance explained by the model was 56%,  $F(11, 119) = 13.64, p < .000$ . The predictors explained an additional 39% of the variance after controlling for age, gender, and ethnicity,  $R$  square change = .386,  $F$  change (8,119) = 12.98,  $p < .000$ . In the final model, two of the predictors were significant including caregiver burden (beta=.519,  $p < .000$ ), and caregiver health (beta=.261,  $p < .000$ ). The part correlation coefficient of caregiver burden was .406, uniquely explaining 16% of the variance. The part correlation coefficient of caregiver health was .240, explaining 6% of the variance. The model summary can be viewed in Table 10.

### **Research Question Five**

The same hierarchical regression analyses procedure was used to assess whether caregiving demands, length of time caregiving, social support, coping, and caregiver burden contributed to the prediction of compassion satisfaction in family caregivers after controlling for the influence of age, gender, and caregiver health. Preliminary analyses were conducted to ensure no violation of assumptions of normality, linearity, multicollinearity, and homoscedasticity. Age, gender, and caregiver health were entered in Step 1 and model 1 was not significant,  $p = .292$ . After entering caregiving demands, length of time caregiving, social support, coping and caregiver burden at Step 2, model 2 was significant and the total variance explained by the model was 22.7%,  $F(11, 119) =$

**Table 10**  
*Hierarchical Regression: Secondary Traumatic Stress*

<b>Model Summary<sup>c</sup></b>									
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.414 <sup>a</sup>	.172	.152	.68809	.172	8.778	3	127	.000
2	.747 <sup>b</sup>	.558	.517	.51943	.386	12.983	8	119	.000

a. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?

b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support

c. Dependent Variable: transformed sq rt sts subscale

<b>ANOVA<sup>a</sup></b>						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	12.468	3	4.156	8.778	.000 <sup>b</sup>
	Residual	60.130	127	.473		
	Total	72.598	130			
2	Regression	40.491	11	3.681	13.643	.000 <sup>c</sup>
	Residual	32.107	119	.270		
	Total	72.598	130			

a. Dependent Variable: transformed sq rt sts subscale

b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?

c. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support

2.97,  $p = .002$ . The predictors explained an additional 14% of the variance after controlling for age, gender, and caregiver health,  $R$  square change = .143,  $F$  change (8, 119) = 3.535,  $p < .001$ . In the final model, three predictors were significant including caregiving demands (beta = .272,  $p = .008$ ), caregiver burden (beta = -.247,  $p = .019$ ), and coping pattern of behavioral disengagement (beta = -.208,  $p = .038$ ). The part correlation coefficient of caregiving demands was .220, uniquely explaining 5% of the variance. The part correlation coefficient of caregiver burden was -.194, uniquely explaining 4% of the variance. The part correlation coefficient of behavioral disengagement was -.170, only explaining 3% of the variance. The model summary can be viewed in Table 11.

### **Additional analyses**

In addition to the analyses conducted as part of the research questions, analyses were conducted to see if other variables contributed to differences in compassion fatigue or compassion satisfaction scores.

**Gender.** In addition to differences in burnout and secondary traumatic stress scores found between males and females questions arose as to what specific factors may contribute to these differences. Questions arose as to whether demographic characteristics related to gender could have influenced the results. Therefore, gender in relation to age, employment, and income was explored further. Cross tabulations were conducted and results indicated that 62.9% of males were over the age of 60, with more females ( $n = 57$ ; 55.9%) being equal to or less than 59. In relation to employment, the majority of males worked full time ( $n = 20$ ; 47.6%) or were retired ( $n = 19$ ; 45.2%). This compared to females who worked full time ( $n=39$ ; 32.2%) and those who were retired ( $n = 44$ ;

**Table 11**  
*Hierarchical Regression: Compassion Satisfaction*

Model Summary <sup>c</sup>									
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.170 <sup>a</sup>	.029	.006	7.28355	.029	1.256	3	127	.292
2	.464 <sup>b</sup>	.215	.143	6.76353	.186	3.535	8	119	.001

a. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?

b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support

c. Dependent Variable: compassion satisfaction total score

ANOVA <sup>a</sup>						
Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	199.941	3	66.647	1.256	.292 <sup>b</sup>
	Residual	6737.360	127	53.050		
	Total	6937.301	130			
2	Regression	1493.612	11	135.783	2.968	.002 <sup>c</sup>
	Residual	5443.689	119	45.745		
	Total	6937.301	130			

a. Dependent Variable: compassion satisfaction total score

b. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?

c. Predictors: (Constant), How would you rate your health?, What is your gender?, What was your age in years on your last birthday?, count of total tasks, behavioral disengagement, instrumental support, denial, self blame, burden total scale score, On average, how many hours per week do you spend caregiving?, emotional support

36.4%). There were more females who worked part time ( $n = 21$ ; 17.4%) or who were not employed ( $n = 15$ , 12.4%) compared to men who worked part time ( $n = 2$ ; 4.8%) and those who were not employed ( $n = 1$ ; 2.4%). Regarding income, the majority of males reported incomes of \$100,000 or more ( $n = 12$ , 28.6%) compared to females ( $n = 20$ ; 16.7%) Independent t-tests were used to examine differences between males and females regarding the number of years caregiving, the hours per week spent caregiving, caregiver health status, and the type of care provided; ADL, IADL, complex clinical tasks, and total number of caregiving tasks. Results indicated that number of complex clinical tasks were the only significant result. Males ( $M = 1.74$ ,  $SD = 1.73$ ) reported performing fewer complex clinical tasks than females ( $M = 2.5$ ,  $SD = 2.05$ ;  $t(161) = -2.169$ ,  $p = .032$ , two tailed). The magnitude of the differences in the means (mean difference =  $-.766$ , 95%  $CI$ :  $-1.46$  to  $-.068$ ) was small (eta squared =  $.03$ ). Although not statistically significant, women ( $M = 53.16$ ,  $SD = 56.16$ ) provided on average of 10 more hours of care per week compared to men ( $M = 43.10$ ,  $SD = 56.16$ ).

**Caregiving hours per week.** An independent sample t-test was conducted to compare the scores on the ProQOL subscales with the number of hours per week the caregiver provided care. Participants were divided into two equal groups (Group 1: 25 hours per week or less, Group 2: Greater than 25 hours per week). Significant differences were found in relationship to burnout and secondary traumatic stress. Those who spent less time caregiving per week; Group 1 ( $M = 22.56$ ,  $SD = 5.93$ ), scored lower on burnout and were significantly different from Group 2 ( $M = 26.44$ ,  $SD = 6.59$ ;  $t(158) = -3.916$ ,  $p = .000$ , two tailed). The magnitude of the differences in the means (mean difference = -



3.879, 95% *CI*: -5.84 to -1.92) was very small (eta squared = .007). For secondary traumatic stress, Group 1 ( $M = 19.97$ ,  $SD = 6.21$ ) also was significantly different from Group 2 ( $M = 24.43$ ,  $SD = 7.17$ ;  $t(158) = -4.136$ ,  $p = .000$ , two tailed). The magnitude of the differences in the means (mean difference = -.473, 95% *CI*: -.699 to -.247) was moderate (eta squared = .098).

**Caregiver health status.** A one way between groups analysis with conducted to explore whether the caregivers' health status impacted compassion fatigue and compassion satisfaction scores using the ProQOL instrument. Participants were asked how they characterized their own health; Group 1 (excellent), Group 2 (good), Group 3 (fair) and Group 4 (poor). There were statistically significant differences between groups at the  $p < .05$  in burnout:  $F(3, 164) = 3.307$ ,  $p = 0.02$ ; and secondary traumatic stress:  $F(3, 164) = 8.607$ ,  $p = .000$ . Effect size for these differences were calculated using eta squared. For burnout, the eta squared = .06 or a moderate effect. Eta squared for secondary traumatic stress was .14 indicating a large effect. Post hoc comparisons using Tukey HSD test indicated that the mean scores for burnout in the Group 1 ( $M = 22.91$ ,  $SD = 5.22$ ) were significantly different than Group 3 ( $M = 25.82$ ,  $SD = 7.01$ ) and Group 4 ( $M = 31.00$ ,  $SD = 6.90$ ). For secondary traumatic stress, results were the same; Group 1 ( $M = 19.65$ ,  $SD = 6.16$ ) were significantly different than Group 3 ( $M = 26.93$ ,  $SD = 6.97$ ) and Group 4 ( $M = 29.67$ ,  $SD = 5.5$ ).

**Caregiving demands.** A one way between groups analysis with conducted to explore whether the number or complexity of caregiving tasks performed impacted compassion fatigue and compassion satisfaction scores using the ProQOL instrument.

Caregiving demands were divided into three categories to reflect complexity of caregiving tasks; ADL, IADL, and complex clinical tasks. Then, within each category of the caregiving demand, groups were created based on the number of activities a participant indicated they performed. For the caregiving demands of ADL; Group 1 ( $\leq 2$  tasks), Group 2 (3-4 tasks), and Group 3 (5 or more tasks); statistically significant differences were found at the  $p < .05$  between the three groups for secondary traumatic stress:  $F(2, 165) = 2.65, p = 0.012$ . The effect size was determined to be small by the eta squared = .05. Post hoc comparisons using the Tukey HSD test indicated that Group 1 ( $M = 20.86, SD = 6.89$ ) was significantly different from Group 2 ( $M = 24.53, SD = 1.12$ ).

For the caregiving demands of IADL participants were divided into four groups; Group 1 ( $\leq 2$  tasks), Group 2 (3-4 tasks), Group 3 (5-6 tasks) and Group 4 (7 or more tasks). Results indicated statistically significant differences at the  $p < .05$  with the compassion fatigue subscales of burnout and secondary traumatic stress. For burnout:  $F(3, 164) = 3.64, p = 0.014$ . The effect size was determined to be small by the eta squared = .06. Post hoc comparisons using the Tukey HSD test indicated that Group 1 ( $M = 20.59, SD = 5.39$ ) was significantly different from Group 4 ( $M = 25.86, SD = 7.29$ ). For secondary traumatic stress:  $F(3, 164) = 4.23, p = 0.007$ . The effect size was determined to be small by the eta squared = .07. Similar to burnout, post hoc comparisons for the secondary traumatic stress subscale using the Tukey HSD test indicated that Group 1 ( $M = 17.79, SD = 4.31$ ) was significantly different from Group 4 ( $M = 23.97, SD = 7.20$ ).

For the complex clinical tasks, groups were created, Group 1 ( $\leq 2$  tasks), Group 2 (3-4 tasks), Group 3 (5-6 tasks) and Group 4 (7 or more tasks), and statistically

significant differences were noted only in compassion satisfaction,  $F(3, 164) = 3.545$ ,  $p = 0.016$ . Effect size for these differences were considered moderate by the eta squared = .06. Post hoc comparisons using Tukey HSD test were conducted, however, analyses were unable to determine which groups differed. However, compassion satisfaction scores were higher in groups with more clinical tasks, Group 2 ( $M = 36.65$ ,  $SD = 7.19$ ), Group 3 ( $M = 33.58$ ,  $SD = 7.36$ ), and Group 4 ( $M = 37.83$ ,  $SD = 5.7$ ) compared to Group 1 ( $M = 32.86$ ,  $SD = 7.14$ ) indicating more satisfaction was reported when performing a higher number of clinical complex tasks.

Although the complexity of tasks performed by the family caregiver did not contribute to differences in compassion fatigue, questions arose as to whether the total number of tasks being performed by the caregiver would contribute to differences in compassion fatigue. Groups were created using quartiles based on the total number of tasks performed: Group 1 ( $\leq 6$  tasks), Group 2 (7 to 10 tasks), Group 3 (11-14 tasks) and Group 4 (15 or more tasks). Statistically significant differences were found in burnout  $F(3, 164) = 6.81$ ,  $p = .000$ , and secondary traumatic stress  $F(3, 164) = 7.85$ ,  $p = .000$ . Effect size for these differences were considered moderate for burnout, eta squared = .11 and moderate for secondary traumatic stress, eta squared = .13. Post hoc comparisons using Tukey HSD test were conducted and in both burnout and secondary traumatic stress groups 1 and 4 differed significantly. In burnout, Group 1 ( $M = 21.30$ ,  $SD = 5.60$ ) was significantly different from Group 4 ( $M = 26.41$ ,  $SD = 7.47$ ) and in secondary traumatic stress Group 1 ( $M = 18.60$ ,  $SD = 6.19$ ) was significantly different from Group 4 ( $M = 23.88$ ,  $SD = 7.27$ ).

## Chapter Five: Discussion

The purpose of this study was to examine the concept of compassion fatigue and compassion satisfaction among family caregivers using a cross sectional descriptive survey design with a convenience sample. A second purpose was to explore the relationship between caregiver burden and compassion fatigue and to determine which characteristics were predictive for the level of compassion fatigue in primary family caregivers for care recipients with chronic disease.

This study aimed to examine the relationships of study concepts guided by Pearlin's stress process model. Since no studies were found that compared the concepts of caregiver burden and compassion fatigue this exploratory study provided descriptive data to determine the level of compassion fatigue and compassion satisfaction in family caregivers, the relationships between outcomes of caregiver burden, compassion fatigue, and compassion satisfaction, and what factors contributed to the level of compassion fatigue.

The specific aims of the study were to examine the positive (compassion satisfaction) and negative (compassion fatigue) outcomes of caregiving in family caregivers and identify factors including caregiver burden, social support, coping, length of time caregiving, caregiving demands, and background context factors that contributed to the level of compassion fatigue.

The following five research questions guided the study:

1. What is the level of compassion fatigue and compassion satisfaction in family caregivers?

2. What is the relationship between caregiver burden and compassion fatigue?
3. Do background context factors (age, gender, ethnicity, employment status, caregiver education, caregiver relationship, income) contribute to differences in compassion fatigue scores?
4. Do caregiving demands, length of time caregiving, social support, coping, and caregiver burden contribute to the prediction of compassion fatigue in family caregivers?
5. Do caregiving demands, length of time caregiving, social support, coping and caregiver burden contribute to compassion satisfaction in family caregivers?

This chapter will discuss findings for each research question followed by a discussion of limitations, implications for practice, and recommendations for future research.

## **Discussion of the Findings**

### **Research Question One**

The level of compassion fatigue and compassion satisfaction according to Stamm (2010) is interpreted as low, average/moderate, or high. As there have been no published studies using the ProQOL-V with family caregivers these results are exploratory. In this study, the level of compassion fatigue and compassion satisfaction in family caregivers revealed that the majority of participants reported a moderate level on compassion satisfaction and burnout, with secondary traumatic stress equally divided between low and moderate levels. Regarding the level of compassion fatigue, 60% of participants reported a moderate level of burnout and 50% indicated a moderate level of secondary

traumatic stress. No participant indicated a high level of burnout or secondary traumatic stress. Additionally, the majority of participants (83%) reported a moderate level of compassion satisfaction, with 14% indicating a high level of compassion satisfaction with very few participants indicating low compassion satisfaction. This indicates that the sample has a fairly high level of compassion satisfaction with moderate to low levels of compassion fatigue.

These results support the qualitative results of Perry et al. (2010) and Ward-Griffen et al. (2011) who indicated that compassion fatigue existed in family caregivers and the concept can be applied to informal caregivers (Day & Anderson, 2011). In addition, results are discussed in relation to individual combination scores on the subscales (Stamm, 2010). The result of high satisfaction, with moderate to low burnout and secondary traumatic stress is the most positive result as it reflects those who receive positive fulfillment from caregiving. Typically those who scored high on burnout in combination with any other score on the subscales are individuals at risk. Specifically, those individuals who score high on burnout and secondary traumatic stress and low on compassion satisfaction are at most risk, exhibit the most distress and need further evaluation (Stamm, 2010). This sample exhibited moderate to high satisfaction, with low to moderate burnout and secondary traumatic stress. Even though this is not the most distressing combination, these caregivers are at risk since the majority scored in the moderate range for all subscales and situational change can impact resultant compassion fatigue and compassion satisfaction. This result indicates that for these participants there

is an opportunity for improvement; for caregivers to increase the level of compassion satisfaction and reduce the levels of burnout and secondary traumatic stress.

### **Research Question Two**

Important to the caregiver experience is the long standing relationship between caregiver and care recipient. Caregiver burden is often conceptualized based on the impact the performed tasks have on caregiver, whereas, compassion fatigue is a concept in which the empathetic relationship between the caregiver and care recipient is foundational to resultant outcomes. The majority of participants in this study (71%) reported high levels of caregiver burden compared to 30% in national estimates (National Alliance for Caregiving & AARP, 2009). This discrepancy may be due to multiple instruments used to measure caregiver burden and similar concepts, the various reported cut scores using the Caregiver Burden Interview, or sample characteristics. One sample characteristic to consider may be that 37% of participants indicated the receipt of hospice services and thus cared for relatives at end of life. Therefore, since approximately a third of the sample population cared for family members with a terminal illness with a life expectancy of 6 months, high caregiver burden would be expected.

To answer the question regarding the nature of the relationship between caregiver burden and compassion fatigue, it was found that there was a strong positive relationship between caregiver burden and burnout and a strong positive relationship between caregiver burden and secondary traumatic stress. This is not surprising as the three concepts represent the negative aspects of caregiving. Interestingly, there was a small negative relationship between caregiver burden and compassion satisfaction whereas, a

stronger negative relationship existed between burnout and compassion satisfaction. This supports literature that caregiver burden can exist without impacting caregiving satisfaction, thus, each representing distinct experiences (Andren & Elmstahl, 2005). Additionally, since the ProQOL consists of three separate subscales with no composite scale score, relationships between the subscales are relevant indicating that the strong negative association between compassion satisfaction and burnout provides support that compassion satisfaction may be protective for burnout as literature suggested (Day & Anderson, 2011; Hooper et al., 2010; Yoder, 2010). This finding supports the premise that caregiver burden and compassion fatigue are similar, but distinct concepts.

Overall, group differences between low and high caregiver burden with compassion fatigue and compassion satisfaction indicated that those with higher caregiver burden had higher burnout and secondary traumatic stress, and those with lower caregiver burden had higher compassion satisfaction. In addition, the high level of caregiver burden reported in this study combined with the moderate to low level of burnout and secondary traumatic stress indicated a relationship exists between the concepts. This finding further supports the position that caregiver burden and compassion fatigue are related but distinct concepts.

### **Research Question Three**

The stress process model (Pearlin et al., 1981) indicated that characteristics of the caregiver can influence the intensity of stress. Therefore, this research explored how background context factors (age, gender, ethnicity, employment status, caregiver



education, caregiver relationship, income) contributed to differences in compassion fatigue scores.

Regarding the negative outcomes of compassion fatigue, findings revealed that gender, employment, income, number of hours per week caregiving, and caregiver health contributed to significant differences in compassion fatigue scores. In this study, women (72%) accounted for the majority of the sample and women reported higher levels of burnout and secondary traumatic stress. Both subscales scores were higher in females than males and a significant correlation was found between gender and burnout. This may be indicative of women's multiple demands as they are increasingly employed outside the home and continue to provide the majority of family caregiving. Although not significant, men ( $M = 35.19$ ,  $SD = 7.14$ ) reported more compassion satisfaction than women ( $M = 33.86$ ,  $SD = 7.00$ ) in this study, therefore, adding to the support that compassion satisfaction is protective of burnout and secondary traumatic stress.

It also appears that variables that influence the caregivers' ability to perform caregiving demands may impact compassion fatigue. Employment status and the number of hours per week caregiving contributed to significant differences in burnout and secondary traumatic stress. In this study, the majority of the sample was retired (38%) or worked full time (35%). Although differences were significant for burnout and secondary traumatic stress scores and resulted in a moderate effect, analysis did not reveal which groups were significantly different. However, although not significant ( $p = .051$ ) those retired and those working full-time seemed to be the most different for burnout. Caregivers who worked full-time reported more compassion satisfaction, less burnout,

and less secondary traumatic stress than those caregivers who were retired. Questions arise as to what factors related to employment and caregiving may account for these findings. While employment status contributed to differences related to compassion fatigue, the inability to determine which groups were significantly different may be due to dissimilarity of group sizes. One plausible explanation could be that those who worked full-time did not provide as many hours per week of care which influence the outcomes. Another explanation could be that by full-time employment provided other outlets for support and engagement, and thus contributed less strain on the caregiving relationship. As limited research has been conducted examining compassion fatigue in family caregivers, these reasons are speculative. Therefore, further study is needed to better evaluate this variable.

Length of time caregiving was a variable of interest since it has been proposed that cumulative stress from years caregiving may result in more negative outcomes such as caregiver burden and compassion fatigue (Bainbridge et al., 2009; Coetzee and Klopper, 2010; Figley, 1995; Figley, 2002; Savundranayagam et al., 2011). In this study, the total number of years caregiving did not contribute to differences in compassion fatigue, but the number of hours per week caregiving did suggesting that intensity rather than duration accounted for the major difference in this population. Results found that those providing care for more than 25 hours per week had significantly more burnout and secondary traumatic stress than those working less hours. Therefore, additional variables that may better reflect prolonged exposure and cumulative stress over time should be examined. Identifying factors that contribute to the perception of increased stress and

burden need to be explored to determine if specific characteristics or situations in caregiving may explain this finding.

Caregiver resources of income and caregiver health contributed to differences in burnout and secondary traumatic stress. As expected, those who earned \$100,000 or more reported less burnout and secondary traumatic stress than any other group supporting Morrison (1999) and Jones et al. (2011) positions that available resources buffer the effects of stressors. However, in the analysis, the only groups that were significantly different from each other in burnout were those who earned \$100,000 or more and those who earned \$30,000 to \$49,999. No group differences were significant for secondary traumatic stress. Additionally, better perception of health resulted in less compassion fatigue. Those caregivers who indicated they were in excellent or good health were significantly different in compassion fatigue scores from those who indicated they were in fair or poor health indicating that perceived health was related to the amount of compassion fatigue reported.

In contrast, age was the only caregiver characteristic that resulted in significant differences for compassion satisfaction. The mean age of the sample was 57 years. Equal groups were established and the study found that those 60 years of age and over reported more satisfaction with caregiving than the younger group. Although significant, this was deemed a small effect. In addition, no significant differences related to age were found in burnout or secondary traumatic stress scores. Based on the overall results, the stress process model is supported in that background context factors impact an individual's

response to stress and negative outcomes, however, do not seem to considerably influence positive outcomes of caregiving.

#### **Research Question Four**

Two regression models were generated to examine whether caregiving demands, length of time caregiving, social support, coping, and caregiver burden contributed to the prediction of compassion fatigue in family caregivers. The first model examined burnout and the second model examined secondary traumatic stress, both concepts representative of compassion fatigue.

**Burnout Regression.** After controlling for age, gender, and caregiver health, the model explained 48% of the variance. Variables that were found to make a unique significant contribution to burnout were caregiver burden and behavioral disengagement. Caregiver burden was the largest contributor at 17%; supporting that caregiver burden is a predictor of burnout.

The coping pattern of behavioral disengagement was also a predictor and positively correlated with burnout, indicating that those who used disengagement as a coping mechanism are more likely to exhibit higher levels of burnout. However, the predictor uniquely contributed a small amount (2%) to the model. This supports Figley's (2002) model of compassion fatigue that stated disengagement contributed to the development of compassion fatigue. Although this coping pattern is significant and is supported by Figley (2002) and Pearlin et al. (2002) as being a contributor to variance in caregiving outcomes, the importance is questioned related to the magnitude of contribution.

**Secondary Traumatic Stress Regression.** Similar to burnout, caregiver burden provided the most significant contribution to the prediction of secondary traumatic stress. In addition, caregiver health was identified as another predictor that contributed to the model indicating that those who rated their health as fair or poor reported more secondary traumatic stress than those who characterized their health as good or excellent. Health status of the caregiver may be considered a significant stressor that contributes to the development of compassion fatigue. As secondary traumatic stress reflects the caregivers' own fear and emotions felt when they help or want to help a suffering person (Figley, 1995), caregivers who are in poor health themselves may be at higher risk when they cumulatively experience negative feelings related to both their own health status and the family members' suffering. This finding is congruent with Zarit, Fermia, Kim, and Whitlatch (2010) findings related to caregiver health influencing caregiver outcomes.

#### **Research Question Five**

A final regression model was generated to examine whether caregiving demands, length of time caregiving, social support, coping, and caregiver burden contributed to the prediction of compassion satisfaction in family caregivers. The model explained 22% of the variance. Independent variables that uniquely contributed to the model included the coping pattern of behavioral disengagement, caregiver burden, and caregiving demands. Both behavioral disengagement and caregiver burden were negatively associated with compassion satisfaction suggesting that those who used behavioral disengagement as a coping mechanism and exhibited more caregiver burden had less compassion satisfaction. Interestingly, the total number of caregiving demands or tasks performed during

caregiving was positively associated with compassion satisfaction. Although a small correlation, this suggests that caregivers receive satisfaction from the caregiving duties they perform.

Contrary to the literature, social support was not found in this study to be a predictor for caregiver outcomes as proposed by Wakefield et al. (2012) and Bainbridge et al. (2009). Additionally, social support was not related to positive outcomes as suggested by Fitzell and Pakenham (2010). Even though social supports are often viewed as positive (Chappell & Funk, 2011), it is noted that not all social support offered is received and perceived as beneficial (Hupcey, 1998).

This study found limited significant relationships between both emotional and instrumental support and all ProQOL subscales. Findings revealed that emotional support only had small positive correlation with compassion satisfaction and instrumental support only had a small positive correlation with secondary traumatic stress. In addition, neither emotional nor instrumental support contributed significantly to the prediction of compassion fatigue or compassion satisfaction similar to the results of Smerflia et al. (2007). Reasons for this could be that the majority of participants reported some type of agency support, with only 23% of participants reporting no support from any formal agencies. It may be that the caregiver received other informal supports that were not reported. Another explanation may be that it is not the presence of social support that impacts caregiving outcomes but the frequency, perception, or type of social support received. Finally, the result may be associated with the instrument used to measure social support. It is possible that the instrument was not sensitive enough to identify specific

characteristics of social support since the two subscales of emotional and instrumental support from the Brief COPE was used. Therefore, although social support is found in the literature to be related to caregiver outcomes, the results of this study are inconclusive and further study is warranted.

Coping is another concept in this study that provided limited contribution to study results. Based on the correlation matrix for the Brief COPE instrument (See Table 6), most subscales were weakly correlated, and only those entered into the regression showed moderate correlation. For the most part, the coping subscales viewed as positive patterns were positively correlated with compassion satisfaction and negatively correlated with burnout and secondary traumatic stress. Those coping subscales view as negative patterns were negatively correlated to compassion satisfaction and positively correlated to burnout and secondary traumatic stress. Based on these results, those coping methods viewed predominantly as negative coping patterns exhibited a stronger relationship with compassion fatigue. As Cronbach alpha scores of the Brief COPE measure were low on several subscales, such as self-blame, the findings related to coping may not be reliable in this study. It may be that another measure of coping that identifies coping into groupings such as problem or emotion focused coping (Folkman & Lazarus, 1988) may provide more specificity and representation of coping patterns due to item and instrument construction and thus provide more insight into individual differences in managing stress. This may provide an important indicator for health care professionals to assess for individual coping patterns used and identify those caregivers at higher risk for compassion fatigue.

### **Additional analyses**

**Gender.** Similar to national studies, this study is predominantly female (72%) compared to national estimates of 66% (National Alliance for Caregiving & AARP, 2009). Even though gender resulted in significant differences in burnout and secondary traumatic stress and a small positive correlation was found between gender and burnout, and gender and secondary traumatic stress, it is unclear what factors contributed to these findings. In the analysis of gender demographic characteristics, more females reported working part time or were not employed compared to men. This finding may indicate that women are more likely to alter their work schedules to accommodate caregiving. This finding is supported by national reports (National Alliance for Caregiving & AARP, 2009). In addition, reports indicated that although more men may be providing care, females still provide the majority and most difficult tasks (National Alliance for Caregiving & AARP, 2009). This study supports this observation in that a significant difference between women and men were noted as women provided more complex clinical tasks than men. However, other types of caregiving tasks, total number of caregiving tasks, and years caregiving found no differences. Although not significant, results also indicated that women provided an average of 10 more hours per week caregiving compared to men. Therefore, complexity of tasks and the time spent caregiving may provide insight into the differences experienced by males and females, but similar to results reported by Pinquart and Sorensen (2006) regarding caregiver



burden, gender accounted for small amount of differences in burnout and secondary traumatic stress scores.

**Time Caregiving.** The amount of time spent caregiving per week was associated with differences in both burnout and secondary traumatic stress. Similar to results found regarding caregiver burden (Bainbridge et al., 2009, Kim et al., 2012, Savundranayagam et al., 2011) individuals who spent more time caregiving per week experienced higher levels of burnout and secondary traumatic stress. In this study, caregivers reported spending an average of 50 hours per week caregiving for an average of 7 years, compared to national studies estimates of an average of 20.4 hours per week and 4 years (National Alliance for Caregiving & AARP, 2009). This increase may be due to the high proportion of participants in this study caring for loved ones in hospice (37%), in addition to other chronic conditions such as multiple sclerosis and amyotrophic lateral sclerosis (ALS). It is unclear whether caring for family members with multiple co-morbid factors contributed to increase in the weekly time spent caregiving. An additional explanation may be that providing care at end of life is more intense psychologically and physically, in addition to the time spent caregiving.

In addition, length of time caregiving was not associated with increased levels of burnout and secondary traumatic stress; levels were similar for individuals' caregiving less than 5 years compared to those caregiving over 5 years. Similar to findings in the caregiver burden literature, Garlo et al. (2010) found that although caregiver burden increased over time the relationship was not significant. Therefore, although participants

provided caregiving for extended amounts of time, the impact of time on caregiving outcomes was minimal.

Participants also experienced high levels of caregiver burden, but reported moderate to low levels of burnout and secondary traumatic stress. Figley (1995) and Coetzee and Klopper (2010) stated that progressive and cumulative stress increased the risk of compassion fatigue. However, even though this sample reported high burden and increased length of time caregiving, burnout and secondary traumatic stress was not high as one might expect. Based on these results, the amount of time spent day to day is more important than the number of years caregiving in the development of compassion fatigue. One explanation may be that over time, coping patterns mature and individuals develop more skills to handle caregiving demands and thus are able to manage the stress better over time. Additionally, as Pearlin and Skaff (1996) stated coping methods evolve over time and the variety of coping methods (Pearlin & Schooler, 1978) is more important in managing stress than one particular coping method.

**Caregiver health.** National studies reported that 17% – 35% of caregivers viewed their health to be fair to poor (Feinburg et al., 2011). In this study, the majority indicated their health was good (59.5%). However, similar to the lower range of national estimates, 18% reported their health as either fair or poor. Caregiver health was found to have significant differences in burnout and secondary traumatic stress in those individuals who perceived their health as good or excellent, from those who perceived their health poor to fair. Caregiver health was also found to be predictive of secondary traumatic stress accounting for 6% of the variance. Questions remain as to the relationship between

caregiver health and compassion fatigue. For example, could it be that the caregiving role contributed to caregivers' poor health or it is possible that the decline in the caregivers' health contributed to increased stress that resulted in increased levels secondary traumatic stress? Caregiver health status is an important characteristic to assess to ensure that the caregiver not only takes care of the care recipient, but takes care of their own health.

**Caregiving demands.** Caregiving demands were measured by whether the participant indicated they performed a certain number of tasks in the categories of ADL, IADL, complex clinical tasks or total caregiving demands. Analysis revealed that each of the four categories resulted in significant difference in one or more of the ProQOL subscale scores. An increase in ADL tasks resulted in an increase in secondary traumatic stress. Furthermore, IADL tasks and the total number of tasks resulted in differences in scores for both burnout and secondary traumatic stress. This supports Pearlin et al. (1981) position that caregiving demands are primary stressors that can lead to other secondary stressors that can contribute to negative consequences. In addition, these results for compassion fatigue are similar to results found in caregiving studies that the type and quantity of tasks increased caregiver burden (Garlo et al., 2010; Kim & Shultz, 2008; Wakefield et al., 2012).

In contrast, clinical complex tasks resulted in an increase in compassion satisfaction suggesting that caregivers feel positively about the complex tasks they perform and receive satisfaction from these tasks. Complex clinical tasks represent a new area of inquiry associated with caregiving. Although acknowledged that family caregivers are performing complex tasks at home (Reinhard et al., 2012), little research

has been conducted to assess the impact on the caregiver. No instrument currently exists to specifically measure the concept related to complex clinical tasks. Although preliminary, it is promising that caregivers reported increased satisfaction from these tasks and further evaluation is needed regarding caregiver impact. Overall, caregiving demands in relation to the type of care provided was found to have significant differences in relation to compassion fatigue scores and thus warrants further investigation.

### **Limitations**

Several limitations of this study including the cross sectional design, unknown influence of other variables, selection bias, and the recruitment and sampling strategy in the study affected the generalizability of results. The cross-sectional design examined family caregivers at one point in time that may not accurately reflect the positive and/or negatives outcomes under study. This is an accepted limitation due to the design of the study.

Secondly, other variables may exist that were not examined in this study may impact the results. The quality of the relationship between the caregiver and care recipient may have influenced the results. Feelings of obligation to provide care for a family member or a past poor relationship with the care recipient as Wuest (2001) described may influence feelings related to whether caregiving results in positive or negative outcomes. Although asked about medical problems of both the care recipient and caregiver, unreported psychological problems such as depression or other medical conditions may not have been reported which could have contributed to study results.

Another limitation considered is related to selection bias of the family caregivers who participated in the study. Demographic characteristics including education and ethnicity may have contributed to these findings. Since the majority of participants had at least some college education and it is recognized that there was a lack of representation of all ethnic groups, how these variables influenced the findings is unknown. Also, since the primary method of data collection was web based, it is recognized that access to the study survey may have been limited in some ethnic and age groups. In addition, it is noted that participants self-selected to participate in the study, therefore, the results found of low to moderate burnout and secondary stress may be related to the possibility that participants who had higher levels of burnout and secondary traumatic stress may not have participated in the study.

Finally, a low response rate (3%) occurred from the original agencies that agreed to recruit participants. One reason for this low response may be that one agency had a large global client list of family and friends that were invited to participate for which the survey may have been irrelevant. As a result, it was unclear how many of those family and friends were actually caregivers. After initial data collection, additional recruitment strategies were identified that included the addition of other agencies in North Carolina and nationally, plus a snowball sampling strategy aimed to recruit family caregivers that were difficult to reach. This second strategy provided additional participants to reach the power needed; however, a response rate could not be calculated. Although the sample was limited predominantly to one geographic area, the second recruitment strategy

expanded this limitation; however, it is unlikely that the additional participants resulted in a large geographic expansion.

### **Implications for Practice**

In an effort to understand the caregivers' experience and provide services that continue to allow the caregiver to provide care to their loved one, health care systems must develop processes to support family caregivers. Individual assessment and intervention development are key elements needed to achieve this goal. Better understanding of caregiver characteristics and the caregiving experience can aid the healthcare professional to develop strategies to address the individual and specific needs of caregivers.

In this study, caregiver burden, behavioral disengagement, caregiving demands and caregiver health emerged as significant to identify individuals' compassion fatigue or compassion satisfaction level. Other significant characteristics found as important indicators for compassion fatigue included gender, employment, income, and the amount of time per week caregiving. Assessment processes can be directed to alert healthcare professionals to focus on these areas to determine who may be at greatest risk for compassion fatigue. For example, asking the caregiver questions focused on their own health status, how much time per week they spend caregiving, and the types of activities they perform may alert the healthcare professional as to caregivers at risk for compassion fatigue.

Although not significant for this study, social support and overall coping methods need further study to determine their relationship to compassion fatigue and compassion

satisfaction to lead to the development of targeted interventions. This supports the position that all caregivers will not necessarily benefit from the same interventions; therefore, each caregiver needs to be individually assessed so that specific interventions can be designed to meet the individual caregiver's needs (Zarit, Femia, Kim & Whitlach, 2010).

As social support has been identified as a buffer for stress (Pearlin et al., 1990) and an intervention for caregivers to prevent and treat compassion fatigue (Figley, 2002) this remains a viable variable of interest. As current interventions often focus on provision of emotional and/or instrumental support, other interventions need be considered to address other aspects of the caregiving experience. For example, in this study the coping pattern of behavioral disengagement was found to be a predictor in both burnout and compassion satisfaction. Therefore, assessment of coping methods used by a caregiver and interventions aimed to support counseling services and the development of more positive coping mechanisms may be warranted. Although coping has been found to be associated with specific caregiving outcomes (Barbosa et al. 2011, Kneebone & Martin, 2003; Lim & Zebrack, 2004, Pearlin et al., 1997; Pearlin et al., 1990), this study found that Carver's 14 coping subscales were marginally correlated with the ProQOL subscales with the exception of those included in the regression models; denial, behavioral disengagement, and self-blame.

Questions therefore remain as to whether social support and coping patterns are significant contributors to compassion fatigue or not. Based on previous evidence available, social support and coping should remain as intervention strategies; however,

caution should be used not to solely focus on these variables since this study did not find strong associations with compassion fatigue or compassion satisfaction. These results were more similarly aligned with Chronister et al. (2010) who reported few associations between coping and caregiver outcomes. This questions the role social support and coping actually play in the outcomes of compassion fatigue and compassion satisfaction.

Theoretically, this study provides support for the use of compassion fatigue and compassion satisfaction compared to caregiver burden when examining the family caregiver experience. First, it is important to note that participants (86%) indicated that they experienced both positive and negative feelings related to caregiving. Very few (2.4%) reported that they had only experienced negative feelings in relationship to caregiving. In addition, the ProQOL scores of moderate to high compassion satisfaction and moderate to low compassion fatigue support the idea that family caregivers experience both positive and negative outcomes from the caregiving.

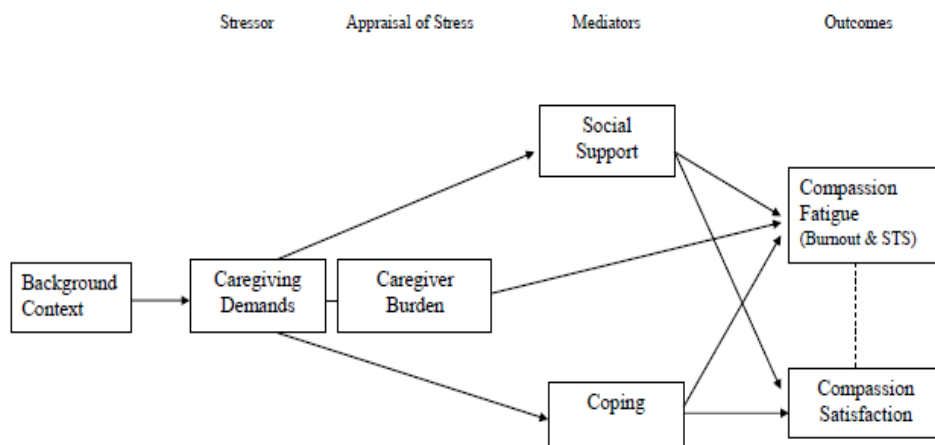
Current literature reflects the lack of clarity of whether caregiver burden should be analyzed as a stressor, predictor, or outcome in caregiving studies. Results from this study suggested that caregiver burden may be best viewed as a stressor based on the strong positive and predictive relationship found with caregiver burden and compassion fatigue. In addition, the lack of significance related to years of caregiving reflecting progressive and cumulative stress may indicate that it is not the sheer presence of stress over time but the caregivers' negative appraisal of stress, such as caregiver burden, that better reflects this dimension. Finally, in this study, although caregiver burden was high, caregivers reported moderate to high satisfaction and low to moderate burnout indicating



that caregivers are able to provide caregiving to family members despite the presence of high caregiver burden. This adds to the support that caregiver burden may be more reflective of a stressor than an outcome.

Results also indicated that compassion satisfaction had a moderate to large, negative association with burnout. Since those with higher compassion satisfaction had lower levels of burnout, compassion satisfaction may be viewed as a protective mechanism. Conversely, limited support existed for compassion satisfaction as being protective of caregiver burden since only small, negatively correlated relationship existed. This provides support for Figley's (2002) compassion fatigue model, and the positions posed by Bastawrous (2013) and Pearlin et al. (1990) that caregiver burden should be viewed as a stressor or an appraisal of stress resulting in caregiving outcomes (Chronister & Chan, 2006; Fletcher et al., 2012). A revised concept model was developed to reflect these changes (See Figure 2). This analysis may indicate that the caregiving outcomes of compassion satisfaction and compassion fatigue may better gauge when a caregiver approaches the inability to provide care for their family member. As a result, interventions aimed to increase compassion satisfaction and reduce caregiver burden may therefore prevent and treat compassion fatigue.

Figure 2: Revised Concept Model



Adapted from Pearlin's Stress Process Model

### Recommendations for Further Research

Further research needs to address caregiver demographics to determine if certain characteristics such as gender or ethnicity place a caregiver at a higher risk for compassion fatigue. Although results indicated that gender differences existed, gender was not deemed a predictor in burnout or secondary traumatic stress. Further examination of gender differences related to the caregiver and the caregiving relationship could provide explanations to differences noted. Additionally, gender of the care recipient and caregiver was not a relationship that was explored. This aspect in addition to the quality

of the relationship may provide additional insight. Ethnicity for this sample similarly compared to national estimates with the exception of Hispanic population. For this sample, the Hispanic population only comprised on 1.2% compared to 12% nationally (National Alliance for Caregiving & AARP, 2009). Cultural factors related to caregiving ideology and the family may impact the level of compassion fatigue and compassion satisfaction due to how different ethnic groups identify and manage stressors suggested by Pearlin et al. (1990). Therefore, further investigation regarding caregiving and ethnicity needs to be examined.

It is important that caregivers continue to provide care for their loved ones. Therefore, caregiving demands are an area of further exploration. The results of this study indicated that caregiver burden, a stressor and appraisal of caregiving demands, is a predictor of compassion fatigue and compassion satisfaction. Although specific caregiving demands, such as ADL, IADL, complexity and total amount of caregiving demands, indicated that differences existed in relation to caregiving outcomes, continued examination regarding characteristics of caregiving demands that lead to the overall assessment of burden is needed to determine at what point caregiver burden leads to the compassion fatigue outcomes of burnout and secondary traumatic stress. Further insight into caregivers' experience may lead to strategies for early identification of situations that place caregivers' at an increased risk for compassion fatigue, thus resulting in the development of caregiving interventions targeted to reduce the stress and caregiver burden associated with caregiving demands to prevent compassion fatigue.

Since only 22% of the variance was explained by the compassion satisfaction regression model, exploration into other variables that could predict compassion satisfaction is needed. Study results provided little insight into variables that influenced compassion satisfaction. Although age and complex clinical tasks contributed to differences and the total number of caregiving tasks performed predicted compassion satisfaction scores, questions arise as to what about these variables contributed to compassion satisfaction. For example, how do the characteristics of caregiving demands contribute to compassion satisfaction? How does a specific task or task categorization contribute to compassion satisfaction or compassion fatigue? Does providing certain types of care increase caregiver self-esteem resulting in increased satisfaction? Further study related to characteristics, behaviors, or situations that contribute to the positive outcomes of caregiving need further exploration. If compassion satisfaction is protective of burnout and secondary traumatic stress, identification of strategies to increase the satisfaction gained from caregiving is an important area for intervention development.

Finally, it must be noted that the ProQOL V is a measure constructed for professional caregivers, not family caregivers. With the increased presence of missing data on the ProQOL subscales compared to the other measures in the study, questions emerge as to whether participants lacked understanding of items based on language or context? For example, one item which had the largest number of missing data were on the secondary traumatic subscale was “I can’t recall important parts of my work with trauma victims.” This item specifically references “my work” and “trauma victims” which likely has no reference to family caregivers. Although memory problems are an important

feature related to secondary traumatic stress, the wording of the item may have not been understood by participants and thus not answered. Additionally, several items referenced “work”. Even though directions for completion of the instrument directed participants to view their caregiving as “work”, confusion may have existed and resulted in participants not answering certain questions if they did not perceive their caregiving as work.

Therefore, further exploration in item revision should be considered to determine if it can be revised to better reflect the concepts for family caregivers.

Overall, this study adds to the current body of caregiving literature related to issues identified such as the lack of conceptual clarity of caregiver burden (Bainbridge et al., 2009; Bastawrous, 2013), limited scope of reference in examining only the negative aspects of caregiving (Bastawrous, 2013; Hunt, 2003) and the use and application of the ProQOL measure with family caregivers. Results of this study support further use and evaluation of compassion fatigue and compassion satisfaction as alternate concepts to explore when investigating the family caregivers’ experience.

### **Conclusion**

The purpose of this study was to examine the concept of compassion fatigue among family caregivers using a cross sectional descriptive survey design with a convenience sample. A second purpose was to explore the relationship between caregiver burden and compassion fatigue and to determine which characteristics were predictive for the level of compassion fatigue in primary family caregivers for care recipients with chronic disease. Based on the results of this study, a revised conceptual model guided by Pearlin’s stress process model was developed to support the use of compassion fatigue

and compassion satisfaction as caregiving outcomes for family caregivers. Characteristics were identified that resulted in differences found in compassion fatigue and compassion satisfaction scores with caregiver burden as the primary predictor that explained a substantial amount of variance in compassion fatigue scores. These results add to existing literature related to theoretical use of caregiving concepts and provide support for an alternative direction of future study related to compassion fatigue in family caregivers.

The results of this study found that caregivers exhibited a high level of burden while still providing care, functioning in other roles, and perceiving themselves in good health. Although various characteristics impacted the level of compassion fatigue and compassion satisfaction, the results pointed to characteristics of an at-risk family caregiver: female, retired, perceive themselves in fair to poor health, perform over 25 hours of care per week, and exhibit signs of disengagement. The intensity of the caregiving relationship seems more important compared to the duration. Although burdened, this population reported low to moderate burnout and secondary traumatic stress, while experiencing moderate to high compassion satisfaction leading to the supposition that compassion satisfaction may be protective of burnout. Therefore, these findings suggest that despite high caregiver burden family caregivers are able provide care for their family members and find satisfaction in that role. Even though caregiver burden is an important factor, this study supports the use of compassion fatigue and compassion satisfaction as alternative caregiving outcomes to better reflect the family caregiver experience.

As limited previous evidence existed related to compassion fatigue in family caregivers, the results of this study are preliminary and can direct future research to further explore compassion fatigue and compassion satisfaction in family caregivers with the goal to better understand the family caregiver experience. In addition, interventional research aimed to reduce the negative outcomes of compassion fatigue and increase the positive aspects of compassion satisfaction can be designed so that family caregivers can continue to provide the high quality care their family members need.

## List of Appendices

### Appendix A: Background Context Factors Questionnaire

Directions: The following section helps us understand you as a caregiver. Please answer the following questions by filling in the blank or marking the answer that best describes **you** as the caregiver.

1. What was your age in years on your last birthday? \_\_\_\_\_
2. What is your gender?
  - Male
  - Female
3. How would you describe yourself?
  - White
  - Black or African American
  - Asian
  - American Indian or Alaska Native
  - Native Hawaiian or Pacific Islander
  - Two or more races
  - Hispanic or Latino
  - Prefer not to report
4. Which of the following best describes your employment?
  - Full time
  - Part time
  - Not Working
  - Retired
  - Disabled
5. If you are employed, how many hours per week do you work? \_\_\_\_\_
6. Which of the following describes your education history?
  - Less than high school
  - High school
  - Some college or associates degree
  - Bachelor's degree
  - Advanced degrees



7. What is your relationship to the person whom you provide care?
- Spouse or partner
  - Child
  - Other family member
  - Friend or neighbor
8. Which of the following income categories best describes your household income?
- Less than 15,000
  - 15,000 – 29,999
  - 30,000 – 49,999
  - 50,000 – 74,999
  - 75,000 – 99,999
  - 100,000 or more
9. How long have you been providing care or assistance for your family member?  
(Provide your best estimate. Report in years if over 1 year or in months if less than 1 year)?
- \_\_\_\_\_ years  
\_\_\_\_\_ months
10. On average, how many hours per week do you spend caregiving?
- \_\_\_\_\_ hours
11. Which of the following medical diagnosis best describes the family member for which you care? (Select all that apply)
- Stroke or Hypertension
  - Musculoskeletal (arthritis, osteoporosis, etc.)
  - Cardiac disease (heart attack, angina, congestive heart failure, etc.)
  - Diabetes
  - Cancer
  - Lung disease
  - Kidney disease
  - Movement disorder (Parkinson's, etc.)
  - Trauma
  - Traumatic brain injury
  - Neurological disorders (ALS, epilepsy, Epstein Barr etc)
  - Multiple sclerosis
  - Paralysis
  - Congenital conditions (CP, autism, Downs, etc)
  - Gastrointestinal problems
  - Transplant (kidney, liver, stem cell)

- HIV/AIDS
- Memory problems (dementia or Alzheimer's)
- Depression
- Mental illness

12. Which of the following organizations or agencies is providing or has provided you and/or your loved one services or support? (*Select all that apply*)

- Hospice and Palliative Care
- Family Caregiver Support Program
- Joe Martin ALS Association
- Multiple Sclerosis Society
- None
- Other \_\_\_\_\_

**Appendix B: Instrumental Activities of Daily Living, Activities of Daily Living, and Complex Clinical Tasks**

Please indicate which of the following caregiving activities you perform or provide assistance for your family member. (*Select all that apply*).

- Use of the telephone
- Shopping
- Food preparation
- Prepare food for special diets
- Feeding
- Housekeeping
- Laundry
- Modes of transportation
- Medication assistance
- Manage medications including intravenous (IV) and/or injections
- Financial management
- Bathing
- Dressing
- Transfers in and out of chair/bed
- Help with assistive devices for mobility like canes or walkers
- Toileting
- Continence of bowels and bladder
- Use of incontinence equipment, supplies, administer enemas
- Wound care
- Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipments, home dialysis equipment, suctioning equipment)
- Use of meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use of telehealth equipment.
- Operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs)

### Appendix C: Brief COPE Scale

There are lots of ways to try to deal with stress. This questionnaire asks you to indicate what you generally do and feel when you experience stressful events.

Respond to each of the following items using the response choices listed just below. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for YOU--not what you think "most people" would say or do. Indicate what YOU usually do when YOU experience a stressful event.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

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

11. I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12. I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13. I've been criticizing myself.	1	2	3	4
14. I've been trying to come up with a strategy about what to do.	1	2	3	4
15. I've been getting comfort and understanding from someone.	1	2	3	4
16. I've been giving up the attempt to cope.	1	2	3	4
17. I've been looking for something good in what is happening.	1	2	3	4
18. I've been making jokes about it.	1	2	3	4
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20. I've been accepting the reality of the fact that it has happened.	1	2	3	4
21. I've been expressing my negative feelings.	1	2	3	4
22. I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23. I've been trying to get advice or help from other people about what to do.	1	2	3	4
24. I've been learning to live with it.	1	2	3	4
25. I've been thinking hard about what steps to take.	1	2	3	4
26. I've been blaming myself for things that happened.	1	2	3	4
27. I've been praying or meditating.	1	2	3	4
28. I've been making fun of the situation.	1	2	3	4

Adapted from Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), 92-100. doi: 10.1207/s15327558ijbm0401\_6

Appendix D: *Zarit Burden Interview*

Instructions: Please circle the response that best describes how you, the family caregiver feel.

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

friends over because of your relative?					
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *The Gerontologist*. 1980;20(6):649-55

ZBI 12 items: Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: A new short version and screening version. *The Gerontologist* 2001; 41:652-657.

### Appendix E: Professional Quality of Life Index (ProQOL)

When you *provide care for* people you have direct contact with their lives. As you may have found, your compassion for those you *provide care* can affect you in positive and negative ways.

Below are some questions about your experiences, both positive and negative, as a *caregiver*. Consider each of the following questions about you and your current situation. “*Work*” refers to the work you perform as a caregiver.

Select the number that honestly reflects how frequently you experienced these things in the *last 30 days*.

1=Never 2=Rarely 3=Sometimes 4=Often 5=Very Often

	Never	Rarely	Sometimes	Often	Very Often
1. I am happy.	1	2	3	4	5
2. I am preoccupied with more than one person I <i>provide care</i> .	1	2	3	4	5
3. I get satisfaction from being able to <i>provide care for</i> people.	1	2	3	4	5
4. I feel connected to others.	1	2	3	4	5
5. I jump or am startled by unexpected sounds.	1	2	3	4	5
6. I feel invigorated after working with those I <i>provide care</i> .	1	2	3	4	5
7. I find it difficult to separate my personal life from my life as a <i>caregiver</i> .	1	2	3	4	5
8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I <i>provide care</i> .	1	2	3	4	5
9. I think that I might have been affected by the traumatic stress of those I <i>provide care</i>	1	2	3	4	5
10. I feel trapped by my job as a <i>caregiver</i> .	1	2	3	4	5
11. Because of my <i>caregiving</i> , I have felt "on edge" about various things.	1	2	3	4	5
12. I like my work as a <i>caregiver</i> .	1	2	3	4	5



13. I feel depressed because of the traumatic experiences of the people I <i>provide care</i> .	1	2	3	4	5
14. I feel as though I am experiencing the trauma of someone I have <i>provided care</i> .	1	2	3	4	5
15. I have beliefs that sustain me.	1	2	3	4	5
16. I am pleased with how I am able to keep up with <i>caregiving</i> techniques and protocols.	1	2	3	4	5
17. I am the person I always wanted to be.	1	2	3	4	5
18. My work makes me feel satisfied.	1	2	3	4	5
19. I feel worn out because of my work as a <i>caregiver</i> .	1	2	3	4	5
20. I have happy thoughts and feelings about those I <i>provide care</i> and how I could help them.	1	2	3	4	5
21. I feel overwhelmed because my <i>caregiving</i> load seems endless.	1	2	3	4	5
22. I believe I can make a difference through my work.	1	2	3	4	5
23. I avoid certain activities or situations because they remind me of frightening experiences of the people I <i>provide care</i> .	1	2	3	4	5
24. I am proud of what I can do to <i>provide care</i> .	1	2	3	4	5
25. As a result of my <i>caregiving</i> , I have intrusive, frightening thoughts.	1	2	3	4	5
26. I feel "bogged down" by the system.	1	2	3	4	5
27. I have thoughts that I am a "success" as a <i>caregiver</i> .	1	2	3	4	5
28. I can't recall important parts of my work with trauma victims.	1	2	3	4	
29. I am a very caring person.	1	2	3	4	5
30. I am happy that I chose to do this work.	1	2	3	4	5

Adapted from Stamm, B. H. (2009). Professional quality of life: Compassion satisfaction and fatigue version 5 (ProQOL). [www.isu.edu/~bhstamm](http://www.isu.edu/~bhstamm) or [www.proqol.org](http://www.proqol.org).

Appendix F: *Email Recruitment Letter*

We are writing to ask for your participation in a survey that we are conducting as part of a doctoral research study at the University of New Mexico. In addition, as faculty in the School of Nursing at the University of North Carolina Charlotte, we have developed a relationship with <agency name> and request your participation in this important family caregiver study. We are asking family caregivers like you to reflect on your experience as a family caregiver and provide insight regarding both the positive and negative aspects of your experience.

Your response to this survey is very important and will help provide valuable information regarding the experiences of family caregivers. As part of the survey, you will provide information about your caregiving experience so that individualized focused interventions can be developed to promote the positive and prevent negative consequences related to family caregiving.

This is a short survey and should take you approximately fifteen minutes to complete. Please click on the link below to go to the survey website (or copy and paste the survey link into your Internet browser) to complete the survey.

Survey Link:

Your participation in this survey is entirely voluntary and all your responses will be anonymous and kept confidential. No personally identifiable information will be associated with your responses in any reports of the data. Should you have any further questions or comments please contact Susan Lynch at [sulynch@salud.unm.edu](mailto:sulynch@salud.unm.edu) or 704-687-7896.

We appreciate your time and consideration in completing the survey. Thank you for participating in this study! If you know of other family caregivers like yourself, you are welcome to forward this letter of participation and survey link to them. It is only through the help of family caregivers like you that we can provide the healthcare community with information to develop better programs to support you and your family.

Many thanks,  
Susan Lynch, MSN, RN  
Doctoral Student, College of Nursing, University of New Mexico  
Lecturer, School of Nursing, University of North Carolina Charlotte

Dr. Geoff Shuster  
Associate Professor, College of Nursing, University of New Mexico

## **Appendix G: Consent to participate**

### **University of New Mexico College of Nursing Consent to Participate in Research**

#### ***The Family Caregiver's Experience- Examining the Positive and Negative Aspects of Compassion Fatigue and Compassion Satisfaction using the Stress Process Model***

#### **Introduction and Purpose**

My name is Susan Lynch. I am a Nursing Doctoral Student at the University of New Mexico, College of Nursing and a faculty member at the University of North Carolina at Charlotte, School of Nursing. Dr. Geoff Shuster, Associate Professor, at the University of New Mexico, College of Nursing is my faculty advisor. We would like to invite you to take part in my research study, which concerns the experiences of family caregivers caring for adults with chronic disease.

#### **Procedures**

If you agree to participate in my research, I will ask you to complete the attached online survey/questionnaire. The survey will involve questions about your experience as a family caregiver and ask you to provide insight regarding both the positive and negative aspects of your experience. The survey should take about 15 minutes to complete.

#### **Benefits**

There is no direct benefit to you from taking part in this study. It is hoped that the research will provide valuable information from which supportive programs can be developed to assist caregivers like you.

#### **Risks/Discomforts**

There are no known risks in this study, but some individuals may experience discomfort when answering questions. You can refuse to answer any of the questions at any time and are free to exit the survey at any time.

#### **Confidentiality**

Your study data will be handled as confidentially as possible. There are no names or identifying information including your email address associated with this survey. Data will be stored on a secure network with access only granted to the research study personnel. When the research is completed, I may save the data for use in future research done by myself or others. I will retain these records for up to 5 years after the study is over.

#### **Rights**

***Participation in research is completely voluntary.*** You are free to decline to take part in the survey. You can decline to answer any questions and are free to stop taking part in the survey at any time. Whether or not you choose to participate, to answer any particular question, or continue participating in the survey, there will be no penalty to you or loss of benefits to which you are otherwise entitled.

**Questions**

If you have any questions about this research, please feel free to contact me. I can be reached at 704-687-7896 or [sulynch@salud.unm.edu](mailto:sulynch@salud.unm.edu) .

If you have any questions about your rights or treatment as a research participant in this study, you may call the University of New Mexico's Human Protection Research Office at 505- 272-1129.

**If you agree to take part in the research, please click the “Accept” button below and begin the survey.** By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

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