Compassion Fatigue in Adult Daughter Caregivers for Older Adults with Dementia

by

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Nursing
Duke University

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Dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor
of Philosophy in
Nursing in the Graduate School
of Duke University

2013

ABSTRACT

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Abstract

Background: Family caregivers for a parent with dementia often experience negative emotional consequences. These caregivers may also be at risk for compassion fatigue, a concept that was introduced to the health care community as feelings of anger, inefficacy, apathy, and depression resulting from a caregiver's inability to cope with devastating stress. Compassion fatigue was first observed in nurses and later in other caring professionals such as social workers and psychologists and the definition was adapted to focus on prolonged exposure to suffering as one of the primary causes.

Although compassion fatigue has not been studied in family caregivers providing care at home, their experiences, particularly those of adult daughter caregivers for parents with dementia, appear to create a foundation for developing compassion fatigue. For this reason, it was important to investigate compassion fatigue in this growing population of caregivers and this dissertation explored compassion fatigue in daughter caregivers for parents with dementia. The dissertation aims were to: 1) identify common themes across the literature on compassion fatigue and to apply these themes and the existing model of compassion fatigue to informal caregivers for family members with dementia; 2) analyze secondary data from Project ASSIST to substantiate a need for further study of compassion fatigue in adult daughter caregivers of a parent with dementia; 3) explore the feasibility of studying compassion fatigue in family caregivers; and 4) explore compassion fatigue, its contributing factors, and potential outcomes in adult daughter caregivers for parents with dementia.

Methods: The dissertation consisted of three studies. The first study, a review of the literature addressed aim 1 of the dissertation as I applied the established model of compassion fatigue to family caregivers. The second study, a secondary analysis pilot

study addressed aim 2 and aim 3 of the dissertation study. The third study of the dissertation was a qualitative study exploring the concept of compassion fatigue in daughter caregivers for parents with dementia.

Conclusions: The literature review found evidence to support the components of the established model of compassion fatigue and findings suggested additional work was needed on the concept of compassion fatigue in family caregivers. Findings from the secondary analysis provided support for more in-depth exploration of the concept of compassion fatigue in family caregivers. Findings from the larger qualitative study provided support for many of the factors related to compassion fatigue, but also suggested revisions to the established model of compassion fatigue were needed. A revised model was created based upon the findings from this dissertation.

The revised model incorporates the contributing factors and moderators of compassion fatigue found in family caregivers and the model also proposes revised characteristics and outcomes of compassion fatigue. Findings from this dissertation also suggest new areas for research, specifically with all dementia caregivers and caregivers who do not utilize formal or informal support. Additional value from this dissertation derives from the detailed explanation of previous relationship quality, empathy, and caregiving experience. This dissertation is one of a few qualitative studies on compassion fatigue to provide this level of detail and provides a base for future studies of compassion fatigue in all family caregivers.

Dedication

This work is dedicated to my husband, Kevin and my sons, Conor and Oliver.

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1. Introduction

1.1 Compassion fatigue in family caregivers

Forget about your own life and give up any hopes for the future as long as you're a caregiver. Hope will kill your soul. Constant disappointment will destroy you. You can only survive by taking it one day at a time (Alzheimer's Association, 2009b, p. 4).

This quote from an adult daughter caring for her mother with dementia suggests the presence of compassion fatigue. Compassion fatigue is a concept that was introduced to the health care community as feelings of anger, inefficacy, apathy, and depression resulting from a caregiver's inability to cope with devastating stress (Joinson, 1992). Compassion fatigue was first observed in nurses and later in other caring professionals such as social workers and psychologists (Figley, 2002a; McHolm, 2006; Sabo, 2006) and the definition was adapted to focus on prolonged exposure to suffering as one of the primary causes (Figley, 1995). In the professional caregiver literature, compassion fatigue was described theoretically to have an acute onset (Figley, 2002a; Sabo, 2006) and engendered negative emotional responses to caregiving such as helplessness, hopelessness, an inability to be empathic, and a sense of isolation (Adams, Figley, & Boscarino, 2008; Joinson, 1992; McHolm, 2006; Robins, Meltzer, & Zelikovsky, 2009).

Although compassion fatigue has not been studied in family caregivers providing care at home, their experiences, particularly those of adult daughter caregivers for parents with dementia, appear to create a foundation for developing compassion fatigue. Adult children caregivers represent a rapidly growing segment of the caregiving population and need interventions and assistance when suffering negative consequences of caregiving. From 2004 to 2009, the percentage of adult children dementia caregivers increased from 57% to 62%, and their average age

increased from 48 to 51 (Alzheimer's Association, 2009a, 2010). Caregivers for older adults with dementia are often daughters; about 60% of these caregivers are daughters or daughters-in-law (Alzheimer's Association, 2010). For example, one study found 38 of the 51 caregivers (75%) studied were female with an average age of 57 years (Rosa, Ambrogio, Binetti, & Zanetti, 2004). Studies have shown that caregivers for people with dementia experience depression, anxiety, and stress (Aguglia et al., 2004; Cooper, Katona, Orrell, & Livingston, 2008; Croog, Burleson, Sudilovsky, & Baume, 2006; Ott, Sanders, & Kelber, 2007; Rosa et al., 2004; Schumacher, Beck, & Marren, 2006; Taylor, Ezell, Kuchibhatla, Ostbye, & Clipp, 2008; Yaffe et al., 2002) and feelings of resentment, helplessness, and hopelessness, in addition to feeling that they have little free time (Hirschfeld, 2003). Caregivers who have these feelings and experiences on top of the emotionally laden filial caregiving relationship might be suffering from compassion fatigue. For this reason, it was important to investigate compassion fatigue in this growing population of caregivers.

According to Figley (2002a), compassion fatigue is a process beginning when a caregiver experiences concern for a person's suffering. This creates an empathic response in the caregiver and, when coupled with an inability to detach from the caregiving situation and dissatisfaction with helping the care recipient, a resulting compassion stress. Compassion fatigue then develops from compassion stress when the caregiver is continually exposed to suffering, competing life demands, and traumatic memories (Figley & Roop, 2006). In this theory, compassion fatigue is dependent upon an exposure to those who are suffering and occurs in caregivers with excessive empathy and self-sacrifice (Lombardo & Eyre, 2011; Sabo, 2011). Compassion fatigue is distinct from depression or burden because it is a combination of responses to caring for those

who are suffering; namely the feelings of helplessness, hopelessness, isolation, and an inability to be empathic rather than being a singular psychological result.

Potential outcomes of compassion fatigue might be increased depression, burden and caregiver strain, and a decreased feeling of relationship quality for the caregiver (Braun et al., 2009; Schumacher et al., 2008; Steadman, Tremont, & Davis, 2007). Compassion fatigue might then lead to the caregiver relinquishing care, such as premature nursing home admission, and might possibly lead to abuse or neglect (Gainey & Payne, 2006; Pérez-Rojo, Izal, Montorio, & Penhale, 2009).

A recent literature review suggested that the concept of compassion fatigue might be applicable to family caregivers (Day & Anderson, 2011). Only two studies were identified, both of which were qualitative studies, that explored compassion fatigue in family caregivers (Perry, Dalton, & Edwards, 2010; Ward-Griffin, St-Amant, & Brown, 2011); these studies found evidence of compassion fatigue in family caregivers where the care recipient was in a long-term facility (Perry et al., 2010) and among nurses who were also daughter caregivers for parents in long-term care (Ward-Griffin et al., 2011). Perry and colleagues (2010) found caregivers described their role consuming their lives and caregivers also spoke of an overwhelming sadness. Daughters in the study by Ward-Griffin and colleagues (2011) described love and concern for their parents and intense, prolonged caregiving contributed to compassion fatigue. Nurse-daughter caregivers also reported feelings of intense guilt and sleep disturbances related to compassion fatigue (Ward-Griffin et al., 2011). These two studies suggest the presence of compassion fatigue in family caregivers for relatives residing in long-term care, but I identified no published studies that specifically examine compassion fatigue in caregivers providing care for aging relatives who live at home.

Of family caregivers, adult daughters might be at greatest risk for compassion fatigue due to their perception of care recipient suffering, competing life demands, decreased sense of satisfaction, and inability to detach from the caregiving situation. In a study of 251 caregivers, adult child caregivers were found to have a more negative perception of the care recipient with dementia's quality of life than the spousal caregivers (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010). Alzheimer's caregivers also care for longer periods of time than caregivers for other chronic illnesses (Ott et al., 2007); 43% care for one to four years, compared to 33% for other illnesses and 32% care for five years or more, compared to 28% of other caregivers (National Alliance for Caregiving & AARP, 2009). Caring for a parent with dementia was described by one child as "the funeral that never ends" (Meuser & Marwit, 2001, p. 666) and demonstrates a prolonged exposure to perceived suffering.

In addition, child caregivers were more likely to be employed and had additional family burdens such as children or dependents (Conde-Sala et al., 2010). Adult children were more likely to be employed, female, and to be caring for older care recipients, but were less likely to reside with the care recipient than spousal caregivers (Pinquart & Sorensen, 2011). Other studies validate the demands on adult children from empolyment, and include role strain and depressive symptoms for adult child caregivers resulting from work demands (Wang, Shyu, Chen, & Yang, 2011). Adult daughters have more demands on their time and daughter caregivers report a greater number of days with decreased mental health when compared to spousal caregivers (Simpson & Carter, 2013). Women might not continually be able to successfully fill a number of roles and these overwhelming life demands contribute to a risk for compassion fatigue.

While both children and spouses report feelings of grief, adult children also describe feeling angry and frustrated and spouses describe feeling sad (Meuser & Marwit, 2001). Adult caregiving daughters are at particular risk for compassion fatigue due to feelings of anger and frustration while caregiving, the quality of the parent-daughter relationship, the multiple roles caregiving daughters have and subsequent role stress from these roles. The percent of daughters or daughter-in-laws caring for a parent with dementia is higher (Alzheimer's Association, 2010) than any other familial caregiver and therefore daughters are the focus for this study.

Adult daughter caregivers face distinct challenges while caring for parents with dementia and might experience the cascade of events that have led to compassion fatigue in other populations studied to date. When the specific cascade leading to compassion fatigue in familial caregivers is better understood, nurses might intervene and interrupt this process at many points. If the process is not interrupted and the caregiver develops compassion fatigue, there is risk for abuse, neglect, and possible termination of the caregiving relationship (Gainey & Payne, 2006; Pérez-Rojo et al., 2009). Research has demonstrated that individuals cared for at home have lower mortality and morbidity than those in institutional settings, controlling for health status, acute illnesses, and chronic health conditions (Van Houtven & Norton, 2004), and a significant decrease in cost to society (AARP Outreach and Services, 2009; Van Houtven & Norton, 2004). Many religions and cultures value caring for family at home (Clark & Huttlinger, 1998; Han, Choi, Kim, Lee, & Kim, 2008; Park, Butcher, & Maas, 2004) and it is beneficial for the nursing community to support valuable family caregivers to continue providing safe, effective care in the home.

1.2 Theoretical framework

1.2.1 Theory of compassion fatigue

A theory is "a set of statements that tentatively describe, explain, or predict relationships between concepts that have been systematically selected and organized as an abstract representation of some phenomenon" (Powers, 2006, p. 175). Figley (2002b) introduced and established a theory of compassion fatigue. This theory describes and explains the relationships between concepts to represent the psychological phenomenon of compassion fatigue. As shown in Figure 1(Figley & Roop, 2006) and described in detail in Chapter 2, compassion fatigue is proposed as a process and the theory has been the foundation for understanding and exploring compassion fatigue in multiple studies with formal caregivers, particularly nurses (Adams, Boscarino, & Figley, 2006; Boscarino, Figley, & Adams, 2004; Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Keidel, 2002; Perry, Toffner, Merrick, & Dalton, 2011; Yoder, 2010).

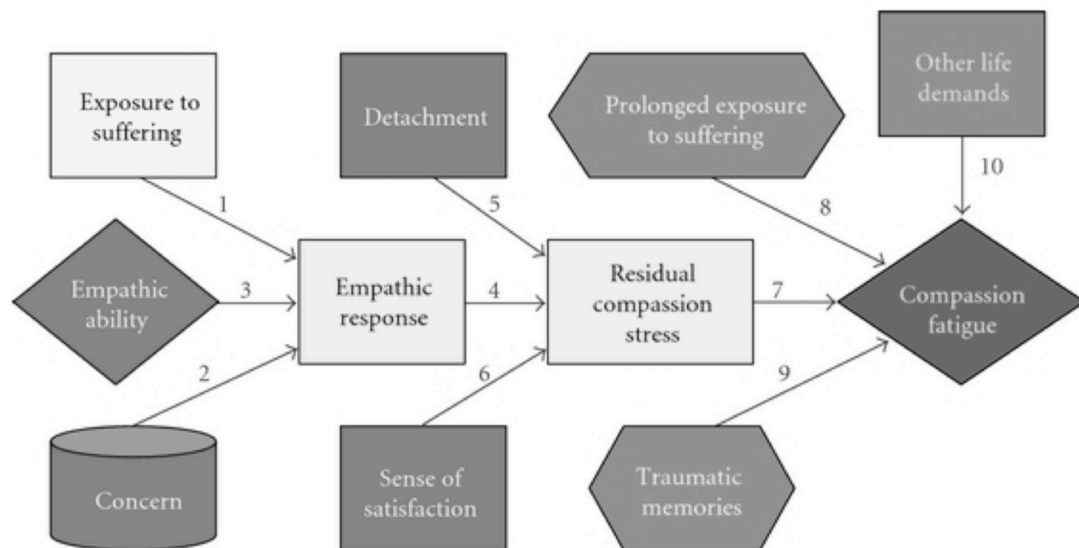


Figure 1: The Compassion Fatigue Process (Figley & Roop, 2006)

The theory of compassion fatigue has generated new hypotheses related to the psychological consequences of providing emotionally demanding care; hypotheses related to secondary traumatic stress (Figley, 1995; Robins et al., 2009; Salston & Figley, 2003) and compassion satisfaction (Hooper et al., 2010; Stamm, 2005; Yoder, 2010) are particularly important developments. Further, new areas of research, such as compassion fatigue in informal caregivers (Day & Anderson, 2011; Perry et al., 2010; Ward-Griffin et al., 2011), emerge from the theory of compassion fatigue. The theory of compassion fatigue is an important tool in understanding the negative consequences of caring for another individual, whether the care provider is a formal or informal caregiver. Therefore, the theory of compassion fatigue guided this dissertation to explore compassion fatigue as experienced by daughter caregivers. The theoretical model was explored and tested for evidence of the concepts in this population. From the findings of this dissertation, I suggest some revisions to the model of compassion fatigue when applied family caregivers.

1.3 Dissertation purpose statement

1.3.1 Specific aims

The dissertation aims were to 1) identify common themes across the literature on compassion fatigue and to apply these themes and the existing model of compassion fatigue to informal caregivers for family members with dementia, 2) analyze secondary data from Project ASSIST to substantiate a need for further study of compassion fatigue in adult daughter caregivers of parents with dementia, 3) explore the feasibility of studying compassion fatigue in family caregivers, and 4) explore compassion fatigue and the contributing factors and potential outcomes of compassion fatigue in adult daughter caregivers for parents with dementia. Each chapter answers one or more aims of the overall dissertation.

1.3.2 Research questions by dissertation chapter

1.3.2.1 Chapter 2: Compassion fatigue: An application of the concept to informal caregivers of family members with dementia

Day, J. and R.A. Anderson, 2011. Compassion fatigue: An application of the concept to informal caregivers of family members with dementia. Nursing Research and Practice

Chapter 2 addresses aim 1, to identify common themes across the literature on compassion fatigue and to apply these themes and the existing model of compassion fatigue to informal caregivers for family members with dementia, and answers the research question: "Is the model of compassion fatigue appropriate for understanding compassion fatigue in informal caregivers?" In this chapter, I applied the concept of compassion fatigue to family caregivers and the literature and found evidence to support the components of the existing model of compassion fatigue.

1.3.2.2 Chapter 3: Compassion fatigue in dementia caregivers at home

Chapter 3 addresses aim 2, to analyze secondary data from Project ASSIST to substantiate a need for further study of compassion fatigue in adult daughter caregivers of parents with dementia, and aim 3, to explore the feasibility of studying compassion fatigue in family caregivers. A secondary qualitative content analysis of six interviews with adult daughter caregivers from Project ASSIST is the first to explore the concept of compassion fatigue among daughters caring for parents with Alzheimer's disease at home. The findings demonstrated evidence for many of the concepts from the model of the compassion fatigue process and suggested a need for a larger study exploring compassion fatigue and its antecedents and consequences in this population.

1.3.2.3 Chapter 4: Compassion fatigue in adult daughter caregivers for parents with dementia.

Chapter 4 addresses aim 4, to explore compassion fatigue and the contributing factors and potential outcomes of compassion fatigue in adult daughter caregivers for parents with dementia. The research questions answered were: 1) "What are the characteristics of compassion fatigue described by adult daughter caregivers for parents with dementia?" 2) "What do adult daughter caregivers for parents with dementia describe as contributing factors and outcomes of compassion fatigue?" and 3) "How do adult daughter caregivers for parents with dementia vary in characteristics of compassion fatigue and contributing factors and outcomes, and what patterns emerge in this variation?" Chapter 4 also presents a detailed description of the research methods for this dissertation study.

A qualitative descriptive design (Sandelowski, 2000) was used to study compassion fatigue as experienced by adult daughter caregivers. This study included open-ended interviews with adult daughter caregivers for parents with dementia. The relative novelty and limited development of this concept lent itself well to a qualitative descriptive method as it allowed for emphasis on exploration into the complexity of compassion fatigue and its contributing factors and outcomes (Barroso, 2010) in a new population. As the central aim of this qualitative study was to develop a detailed description of compassion fatigue in the informal caregiving population, this method, which lacks restrictions from more classical philosophical qualitative approaches, such as ethnography or phenomenology (Artinian, 1988), allowed the researcher to stay closer to the words of participants and to the data (Sandelowski, 2000).

1.4 Summary

Understanding compassion fatigue in this population, how it manifests and its contributing factors and outcomes is a necessary first step to alleviating compassion fatigue for informal caregivers. With the knowledge from this dissertation, nurses will be in a position to identify caregivers at risk for developing compassion fatigue and caregivers already experiencing compassion fatigue. In addition, nurses are skilled at recognizing older adults who are suffering and are in a position to alleviate the suffering, thus decreasing the caregiver's risk for developing compassion fatigue through removing the prolonged exposure to suffering. Prior research on compassion fatigue has focused on health care providers and has overlooked filial caregivers. Likewise, caregiving research has not fully explored the important relationship between parent and child and how this attachment influences the caregiving experience.

This dissertation addresses these existing limitations and the findings were used to describe compassion fatigue and its contributing factors and outcomes in the family caregiving population, to inform practice and research, with a longer-term goal of developing interventions to reduce compassion fatigue. Until compassion fatigue is adequately understood in familial caregivers, it is uncertain if existing caregiving interventions address compassion fatigue. Considering the significance of the emotional attachment and perceived suffering in a caregiver's development or risk for compassion fatigue, interventions targeted to reduce compassion fatigue will likely be different from those to reduce caregiver burden or strain. In attempting to stop the cascade before compassion fatigue begins, interventions aimed at reducing care recipient suffering might be successful. In addition, interventions targeted on strengthening the caregiver and care recipient relationship might also be developed. With the knowledge gained from this study, specific interventions, particularly tailored interventions to address

women at greatest risk, might be designed once more is known about the importance of caregiver and care recipient relationship quality.

2. Compassion Fatigue: An Application of the Concept to Informal Caregivers of Family Members with Dementia

2.1 Introduction

Compassion fatigue was introduced to the health care community as a unique form of burnout experienced by those in caring professions, particularly palliative care and oncology nurses (Joinson, 1992). Later, other health care professions such as social work, medicine, and psychology adopted the concept (Figley, 1995, 2002a; McHolm, 2006; Sabo, 2006). Many definitions of compassion fatigue have been offered by researchers and authors, the most common being that compassion fatigue is an adverse consequence of caring for individuals in need and the caregiver may experience the symptoms of anger, depression, and apathy (Adams et al., 2008; Joinson, 1992; Keidel, 2002). Family caregivers, particularly those caring for older adults with dementia, display many of the characteristics of compassion fatigue. Caregivers for family members with dementia experience depression, anxiety, and stress (Aguglia et al., 2004; Cooper et al., 2008; Croog et al., 2006; Ott et al., 2007; Rosa et al., 2004; Schumacher et al., 2006; Taylor et al., 2008; Yaffe et al., 2002) and also feelings of resentment, helplessness, and hopelessness; in addition to feeling that they have little free time (Hirschfeld, 2003). Caregivers who have these feelings and experiences on top of the emotionally laden filial caregiving relationship may be suffering from compassion fatigue, yet compassion fatigue has not been explored for informal caregivers of family members with dementia.

Informal caregivers for family members with dementia who develop compassion fatigue may terminate the caregiving relationship though premature nursing home admission or relinquishing care to another family member, and there may also be increased risk for abuse or neglect (Schumacher et al., 2006; Taylor et al., 2008).

Supporting these caregivers may improve outcomes for people with dementia because individuals who are cared for at home have lower morbidity and mortality than those in institutional settings (Van Houtven & Norton, 2004), and caring for family members at home provides a significant decrease in cost to society (AARP Outreach and Services, 2009; Van Houtven & Norton, 2004). In order for the professional health care community to support these caregivers, compassion fatigue must be fully explored in this population of caregivers. Therefore, the objective of this paper is to identify common themes across the literature on compassion fatigue and to apply these themes and the existing model of compassion fatigue to informal caregivers for family members with dementia.

2.2 Compassion fatigue: Themes from the literature

Historically, health care literature has not presented a consistent definition of compassion fatigue. Compassion fatigue, a term introduced by Joinson (1992), and developed by Figley (1995) has been defined interchangeably with secondary traumatic stress and secondary traumatic stress disorder, vicarious traumatization, and burnout (Figley, 2002a; Keidel, 2002; McHolm, 2006; Robins et al., 2009), thus creating confusion regarding its definition. For example, authors of a 2008 literature review of compassion fatigue as experienced by cancer-care providers stated that they were unable to generate a definition based on the 14 studies reviewed (Najjar, Davis, Beck-Coon, & Carney Doebbeling, 2009). Table 1 contains the unique definitions of compassion fatigue found in earlier literature from nursing, and all articles by Figley, or authors adapting his definition.

Table 1: Definition of Concepts and Key Terms

Authors, Year	Population	Purpose	Definition of Concepts and Key Terms
Joinson, 1992	Nurses	Description of compassion fatigue, how to recognize it, and how to prevent it	**Compassion Fatigue**: unique form of burnout linked to caregiving professionals, can be emotionally devastating, causes loss of ability to cope, anger, apathy, depression, and ineffectiveness
Figley, 2002	Psychotherapists	To discuss compassion fatigue as experienced by psychotherapists and contrast the concept with burnout and countertransference	**Secondary Traumatic Stress**: the natural behaviors and emotions that arise from caring for someone suffering from a traumatizing event **Compassion Fatigue**: tension and anxiety that occurs from re-experiencing traumatic events with the patient, sense of helplessness and confusion, isolation from support **Burnout**: physical, mental, and emotional exhaustion that occurs from continuous emotionally demanding encounters
Keidel, 2002	Hospice caregivers	To discuss how burnout affects hospice caregivers and to examine causes of stress	**Burnout**: "syndrome of physical exhaustion including a negative self-concept, negative job attitude, and loss of concern and feeling for patients" **Compassion Fatigue**: form of burnout affecting people in caregiving professions, less abrasive term than burnout
Huggard, 2003	Physicians	To shed light on the subject of compassion fatigue in medical education programs	**Empathy**: validating the client's world through understanding the "story behind the story" **Compassion Fatigue**: based on Figley's definition, a sudden stress response with symptoms disconnected from the real cause and being empathic places someone at risk

Authors, Year	Population	Purpose	Definition of Concepts and Key Terms
McHolm, 2006	Nurses	To use God and scriptures to examine what can be done for nurses experiencing compassion fatigue, and to see how compassion fatigue is different than burnout	**Compassion**: being aware of the suffering of another and the strong desire to alleviate the suffering **Compassion Fatigue**: the emotional, social, and spiritual exhaustion that causes a decline in the desire, ability, and energy to feel and care for others, lost ability to experience satisfaction and joy in profession and personal life **Burnout**: becoming less empathic to patients and displaying negative behaviors to coworkers, "candle that goes out because the wax has been used up"
Sabo, 2006	Nurses	To examine the effects that caring has on nurses' health	**Compassion**: "experience of feeling with another while recognizing that the feelings of one are not the same as another" **Empathy**: awareness of a patient's feelings, sharing this with the patient, and the patient's awareness that the nurse feels this **Compassion Fatigue**: the acute onset of a combination of secondary traumatic stress and burnout **Burnout**: a gradual negative change in professional attitude to job strain
Schulz, et al., 2007	Family caregivers	To discuss the relationship between patient suffering and caregiver compassion	**Suffering**: bearing or undergoing of pain, distress, or tribulation (Oxford English Dictionary, 1989) **Compassion**: sense of shared suffering accompanied by a desire to relieve the suffering **Compassion Fatigue**: the stress, strain, and wariness that arises from caring for a person suffering from a medical or psychological problem

Authors, Year	Population	Purpose	Definition of Concepts and Key Terms
Adams, Figley, & Boscarino, 2008	Social workers	To investigate the differences between secondary traumatic stress and job burnout, and to see if secondary trauma can predict psychological distress	**Compassion Fatigue**: a formal caregiver's inability or disinterest in being empathic or sharing the suffering of clients **Burnout**: the emotional exhaustion, depersonalization and reduced personal accomplishment that arises from prolonged exposure to demanding interpersonal relationship and stressful environments
Marr, 2009	Physicians	A personal reflection	**Compassion**: the suffering with the sufferer that occurs in the moment because of the relationship between beings; what we do, not who we are
Robins, Meltzer, & Zelikovsky, 2009	Physicians, nurses, mental health practitioners, allied health practitioners	To examine the effect providing care has on health care workers and trauma workers, and to examine the relationship between secondary traumatic stress, empathy, spirituality, and coping	**Compassion Fatigue**: the symptoms and emotional responses the occur from caring for traumatized persons, same as secondary traumatic stress and vicarious traumatization

Authors, Year	Population	Purpose	Definition of Concepts and Key Terms
Ward-Griffin, St-Amant, & Brown, 2011	Nurse-daughters caring for elderly parents	To examine compassion fatigue in nurse-daughter caregivers and identify the effect of the environment on compassion fatigue	**Compassion Fatigue**: distinct from burnout, a condition affecting physical, emotional, and social health and well being, "living on the edge" where expectations exceed resources

Several themes arise from the definitions in the literature on compassion fatigue. Compassion fatigue: (a) is dependent on a caring relationship between the caregiver and a care recipient, who is suffering or traumatized (Figley, 2002a; Huggard, 2003; Joinson, 1992; Keidel, 2002; Robins et al., 2009; Schulz et al., 2007); (b) is a form of burnout (Joinson, 1992; Keidel, 2002); (c) has an acute onset (Figley, 2002a; Sabo, 2006); and (d) has negative emotional responses for the caregiver such as helplessness, hopelessness, isolation, and apathy or an inability to be empathic (Adams et al., 2008; Joinson, 1992; McHolm, 2006; Robins et al., 2009). These four themes and Figley's model of the compassion fatigue process (Figley, 2002a) provide a basis for exploring whether compassion fatigue is a concept that applies to informal caregivers for family members with dementia.

2.3 Compassion fatigue: Applied to informal caregivers

As shown in Figure 2 (Figley & Roop, 2006), compassion fatigue is a process. According to Figley's model, the caregiver must have concern and an empathic ability or feel motivated to respond when they perceive that the care recipient is suffering (Figley, 2002a). When caregivers have this empathic response, coupled with an unwillingness or

inability to detach from the caregiving situation and the absence of feelings of satisfaction, the caregiver develops compassion stress (Figley, 2002a). Compassion stress results in compassion fatigue if the caregiver has prolonged exposure to suffering coupled with traumatic memories and competing life demands (Figley, 2002a).

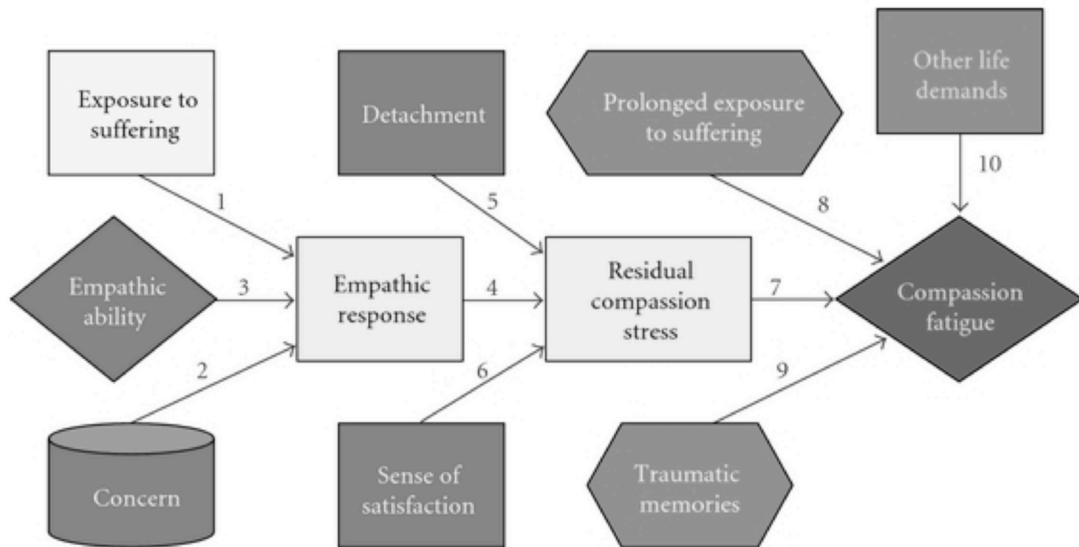


Figure 2: The Compassion Fatigue Process (Figley & Roop, 2006)

Compassion fatigue has not been specifically studied in informal caregivers, but many of the characteristics of compassion fatigue are recognizable in informal caregivers, particularly those caring for family members with dementia. Characteristics of compassion fatigue displayed in formal caregivers include, but are not limited to, apathy, depression, and anxiety (Figley, 2002a; Joinson, 1992; Schulz et al., 2007). Dementia caregivers experience stress and have also been found to experience anxiety and depression (Aguglia et al., 2004; Cooper et al., 2008; Croog et al., 2006; Rosa et al., 2004; Schumacher et al., 2006). It is likely, therefore, that informal caregivers are at risk for compassion fatigue.

To analyze the applicability of the concept to informal caregivers, I apply Figley's model of the compassion fatigue process (Figure 2) (Figley & Roop, 2006) to informal caregivers, explore the possible differences in compassion fatigue between formal and informal caregivers, and use the results of the analysis to suggest future directions for research on compassion fatigue in family caregivers.

2.3.1 Contributing factors of compassion fatigue

2.3.1.1 Empathic ability, concern and attachment

Although compassion fatigue has not been specifically studied in family caregivers for a family member with dementia, their experiences appear to place them at risk for developing compassion fatigue. For example, a loving emotional relationship between care recipient and caregiver is important in the family caregiving dyad and I propose this places the caregiver at particular risk for compassion fatigue. The caregiver-care recipient relationship provides a source for the caregiver's desire to respond to suffering and the caregiver's ability to recognize their family member's suffering. The following quote from a daughter about her relationship with her mother demonstrates an affectionate relationship. "If I didn't love my mother unconditionally, this experience wouldn't hurt so deeply. So I am grateful to have loved truly and deeply and to suffer now, than never to have had such an amazing relationship in the first place" (Alzheimer's Association, 2007, p. 8). Although this daughter does not display compassion fatigue, she may be at risk given her close relationship with her mother.

Premorbid relationship quality impacts the caregiving relationship (Williamson & Schulz, 1995). Research shows that caregivers who had a positive relationship have less strain during caregiving and are able to find meaning in caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990; Lyons, Stewart, Archbold, & Carter, 2009; Mui, 1992). Compassion is attributable to the quality of the relationship between two people

(Marr, 2009). Compassion happens in the moment and is not about how a person is, but what a person does; "It is not something I have, and give to you. It manifests in the relationship between beings" (Marr, 2009, p. 759). The relationship quality is likely central to the reason the caregiver experiences compassion fatigue and provides for the emotional attachment the caregiver has to the care recipient, thus making informal caregivers particularly vulnerable to compassion fatigue. Relationships with an emotional attachment may affect the way the caregiver perceives suffering by the care recipient and influence the amount of empathy that the caregiver feels.

Informal caregivers for family members with dementia may be at an even greater risk for compassion fatigue than formal care providers given the emotional attachment to the care recipient. In the compassion fatigue process, detachment is the ability of the provider to distance themselves from the suffering (Figley, 2002a). The strong emotional attachment between parent and child may prohibit the family caregiver from detaching and therefore removes an essential coping mechanism utilized by formal care providers (Benoit, Veach, & LeRoy, 2007; Figley, 2002a). Thus, emotional attachment is an important aspect for future studies about informal caregivers and compassion fatigue.

2.3.1.2 Exposure to perceived suffering

Studies suggest that caregivers feel that their family member with dementia is suffering, regardless of how much the person with dementia feels himself or herself to be suffering (Monin, Schulz, Feeney, & Cook, 2010; Monin, Schulz, Martire, et al., 2010; Schulz et al., 2007; Schulz et al., 2010). Schulz et al. (2007) found that higher caregiver compassion was related to family member suffering but stated that the worst case occurs when "suffering is chronic and intense with low perceived ability to affect its course" (p. 10). Chronic suffering is particularly true for dementia patients and many family members are helpless to change the trajectory, thus are at greater risk to develop

compassion fatigue. Dementia caregivers care for longer periods of time than caregivers for other chronic illnesses (Ott et al., 2007); 71% care for more than a year and 32% care for five years or more (Alzheimer's Association & National Alliance for Caregiving, 2004). Caring for a parent with dementia was described by one adult child as "the funeral that never ends" (Meuser & Marwit, 2001, p. 666) and demonstrates a prolonged exposure for the caregivers to their family members' suffering.

In addition, a qualitative, secondary analysis of interviews with nurse-daughters caring for elderly parents identified an association between parental suffering and compassion fatigue (Ward-Griffin et al., 2011). One daughter described the difference between caring for a parent versus caring for a non-family member this way, "When I saw my parents suffering, I suffered… When it's your parent and someone you love so intensely, you just want more for them to be safe and healthy" (Ward-Griffin et al., 2011, p. Manuscript 4). There is a clear relationship between the affection or emotional attachment to the parent and the daughter's perception of suffering (Ward-Griffin et al., 2011).

Whereas formal care providers may be able to take time away from people who are suffering (Figley, 2002a; Huggard, 2003; Joinson, 1992; Keidel, 2002; McHolm, 2006), family caregivers may not have this opportunity (Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009; Schulz et al., 2007). This may place family caregivers at a greater risk for compassion fatigue than formal caregivers. In addition, family caregivers are often caring for long periods of time, around-the-clock, and thus this constant exposure to suffering is especially prolonged for informal caregivers for family members with dementia.

2.3.1.3 Sense of satisfaction

Feelings of fulfillment and contentment from caring for a family member with dementia may protect family caregivers from compassion fatigue. Without a sense of satisfaction in caring, however the caregiver is at risk for compassion fatigue. Dementia caregivers are capable of experiencing satisfaction, but their satisfaction results from the family member with dementia's well-being, as well as from receiving appreciation for the care they are providing (Mayor, Ribeiro, & Paul, 2009), both of which are compromised by the dementing condition. There are also racial differences with caregiving satisfaction. A large, multi-site study with 720 participants comparing Caucasian and African American family caregivers found that Caucasian caregivers had a lower perceived benefit from caregiving than the African American caregivers when controlling for socioeconomic status, gender, relationship, and age (Haley et al., 2004). Caucasian caregivers also demonstrated a decrease in life satisfaction over time, whereas the African American caregivers had a continued high level of life satisfaction (Haley et al., 2004). Thus, the race or ethnicity of a caregiver may place him or her at greater risk for compassion fatigue.

2.3.1.4 Traumatic memories

I propose the informal caregiver may develop compassion fatigue without traumatic memories, and this is where application of Finley's model to informal caregivers may diverge from formal healthcare providers. In reviewing the history of the concept of compassion fatigue, the definition has changed from a definition without a focus on traumatic memories (Joinson, 1992) to one that incorporates these elements (Figley, 2002a). Compassion fatigue, according to Joinson, is caused by unavoidable external sources, is difficult to recognize, and leads to a caregiver becoming "angry, ineffective, apathetic, and depressed" (Joinson, 1992, p. 116). Compassion fatigue may

be caused when a nurse encounters more stress than he or she is able to cope with and the nurse's ability to function is compromised (Joinson, 1992). Joinson's definition does not include traumatic memories; this element was added to the definition by Figley when he represented compassion fatigue as a "state of tension and preoccupation with the traumatized patients by re-experiencing the traumatic events, avoidance/numbing of reminders [sic] persistent arousal (e.g., anxiety) associated with the patient" (Figley, 2002a, p. 1435). I propose that some definitions of compassion fatigue exclude the caregiver's own personal traumatic memories and compassion fatigue is therefore applicable to informal caregivers, whether or not they have traumatic memories. Future informal caregiving research may illicit traumatic memories from family caregivers and will allow for the exploration of possible traumatic memories related to caregiving in this population.

2.3.1.5 Life demands

The time caregivers spend on caregiving removes them from other relationships. Informal caregivers for family members with dementia often find themselves alone during the day with their family member, and while this relationship is valuable, it does not replace peer relationships. Caregivers become isolated and often feel there is no one they can talk to about their feelings and that friends cannot relate to them (Neufeld & Harrison, 1998). Hirschfeld's (2003) survey of 30 caregivers found that caregivers felt resentful, helpless, and hopeless, and that they had little free time. When a caregiver has little free time, they are unable to participate in activities focusing on themselves and fostering other relationships.

It is likely that multiple life demands can also contribute to a caregiver developing compassion fatigue. Dementia caregivers are frequently faced with situations of burden and the more dependent the care recipient, the higher the burden

and demands. Layering on the emotional attachment of the family caregiving situation may facilitate development of compassion fatigue in ways that are yet unknown, and likely unique to family caregivers. The life demands of a family caregiver are different from formal caregivers (Hirschfeld, 2003; Neufeld & Harrison, 1998) and I propose that these demands may make it more difficult for family caregivers to avoid developing compassion fatigue. Family caregivers appear to have fewer outlets for support and buffers against the compassion fatigue process than do formal caregivers.

2.3.2 Indicators of compassion fatigue

Our analysis of the literature presenting definitions of compassion fatigue suggests that the indications of compassion fatigue present in formal healthcare providers, such as hopelessness, helplessness, emotional disengagement, and apathy, also are present in caregivers for older adults with dementia. Compassion fatigue is a combination of these factors, not each independently, and may present differently in informal caregivers than it does in formal healthcare providers. The literature on potential indicators of compassion fatigue is presented to help establish whether further research in this area would be fruitful.

2.3.2.1 Hopelessness

Family caregivers, particularly caregivers for older adults with dementia, exhibit hopelessness. Hope is defined as "a feeling of desire for something, usually with confidence in the possibility of its fulfillment" (Collins English Dictionary, 2010). Caregivers who are experiencing hopelessness will feel the impossibility of a desire to be fulfilled. A study of 129 caregivers and 145 non-caregivers in Brazil compared levels of depression, anxiety, hopelessness, and stress (Bandeira et al., 2007). Caregivers had significant differences from non-caregivers on the hopelessness measure, with higher levels of hopelessness (Bandeira et al., 2007). Hopelessness was also associated with

higher levels of anxiety and depression in the caregivers (Bandeira et al., 2007). In this study, the relationship between caregiver and the person with dementia, and stage of dementia were not related to level of hopelessness (Bandeira et al., 2007).

2.3.2.2 Helplessness

Caregivers who feel helpless may also feel powerless in the caregiving situation. Helplessness in caregivers for family members with dementia is associated with the frequency of depressive behaviors in the care recipient, the caregiver's appraisal of these depressive behaviors, and the caregiver's appraisal of disruptive behaviors (Séoud et al., 2007). Caregivers are more likely to feel helpless when they do not understand a family member's depression (Séoud et al., 2007). Male caregivers and Christian caregivers were more likely to have feelings of helplessness compared to female caregivers and Muslim or Druze caregivers (Séoud et al., 2007). Caregivers of family members with cancer describe helplessness and powerlessness, particularly related to the perception of suffering (Milberg, Strang, & Jakobsson, 2004). Participants described suffering not only as pain, but as an existential suffering, including impaired function in daily life, reduced autonomy, and loneliness (Milberg et al., 2004). Helplessness and powerlessness were related to the caregiver's perception of the patient's fading away and feelings of insufficiency (Milberg et al., 2004) and dementia caregivers also report feeling that their family member is fading away (Schulz et al., 2007).

2.3.2.3 Apathy

Apathy is a lack of interest or concern and has been included in the definition of compassion fatigue in professional caregivers (Joinson, 1992). No studies were found that described caregivers experiencing apathy in relationship to caring for family members with dementia. Because there is no research on the concept of compassion

fatigue in family caregivers, the meaning of apathy for this population is yet to be understood.

2.3.2.4 Emotional disengagement or isolation

Caregivers with compassion fatigue may have emotional disengagement, or active withdrawal from and avoidance of the caregiving situation. Emotional disengagement has been explored in spouses of patients undergoing cardiac rehabilitation (O'Farrell, Murray, & Hotz, 2000). O'Farrell, Murray, and Hotz (2000) found spouses who were distressed coped using disengagement strategies significantly more than non-distressed spouses. Qualitative interviews with 10 family caregivers about stigma, particularly family stigma that comes from being associated with a relative with a stigmatic mark (Larson & Corrigan, 2008), revealed that children caregivers who had negative emotions to caregiving, such as embarrassment, shame, and particularly disgust, reported a decrease in involvement. One caregiver stated, "I come to visit her and I see her… like a small bird…toothless…all wrinkled. I approach her but I cannot talk to her, I cannot hug her, kiss her" (Werner, Goldstein, & Buchbinder, 2010, p. 163). Compassion fatigue, like the family stigma that causes the family members of a person with dementia to have feelings of disgust, embarrassment, and decreased involvement, can cause an adult child caring for a parent with dementia to become emotionally disengaged. Being emotionally disengaged is evidence of compassion fatigue.

2.3.3 Consequences of compassion fatigue

Compassion fatigue has negative outcomes for formal caregivers such as depression, isolation; physical symptoms of insomnia, fatigue, or weight changes; and increased errors at work and job dissatisfaction (Figley, 1995, 2002a; Huggard, 2003; Joinson, 1992; Keidel, 2002; Marr, 2009; McHolm, 2006; Najjar et al., 2009; Sabo, 2006;

Ward-Griffin et al., 2011). While the likely consequences of compassion fatigue in informal caregivers have not been explored in research published in the current literature, I propose that compassion fatigue may lead to negative outcomes for both the caregiver and the care recipient. Drawing upon formal caregivers' negative outcomes, and because similar concepts, such as depression and burden, have negative outcomes for informal caregivers, I propose informal caregivers for family members with dementia who develop compassion fatigue may suffer depression, burden, caregiver strain, and a decreased relationship quality with the care recipient. Compassion fatigue may also determine whether or not the caregiver continues to care for their family member with dementia, or if the person with dementia is placed in an institutional setting or cared for by another person.

2.3.3.1 Depression

Informal caregivers for people with dementia are already at risk for depression as found in multiple studies (Aguglia et al., 2004; Andren & Elmstahl, 2005; Sansoni, Vellone, & Piras, 2004; Taylor et al., 2008; Yaffe et al., 2002). Yaffe et al. (2002), in a large, multi-site study of 5,788 patients, found that caregivers with at least six depressive symptoms were 1.18 more times likely to place the care recipient in a nursing home than a caregiver with five or less depressive symptoms. Research suggests a high level of depression among dementia caregivers finding mean score of 21.47 (Martin, Gilbert, McEwan, & Irons, 2006) on the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977) where higher scores are indicative of greater depressive symptomatology and a score of 16 indicates depression (Radloff, 1977).

2.3.3.2 Burden

Caregiver burden is related to competing life demands, and the more competing life demands, the greater the opportunity for both objective and subjective burden. As

discussed, dementia caregivers experience burden (Andren & Elmstahl, 2005; Arai et al., 2004; Arango Lasprilla, Moreno, Rogers, & Francis, 2009; de Moraes & da Silva, 2009; Gainey & Payne, 2006; Hong & Kim, 2008; Raccichini et al., 2009; Steadman et al., 2007) and compassion fatigue could lead to even greater burden; it is also possible that the relationship between burden and compassion fatigue is reciprocal. Further, caregivers for family members with dementia experience burden even when the family member resides in an institution (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). A study of 172 caregivers found caregivers had no significant difference in level of burden related to care recipient residence (Papastavrou et al., 2007). This study also found a relationship between level of education and income to caregiver burden; less educated and lower income caregivers were at greater risk for burden (Papastavrou et al., 2007). Caregiver depression is a major factor related to burden and Papastavrou and colleagues (2007) found 85 caregivers (49.41%) had scores above the risk level for development of clinical depression. Caregivers for family members with dementia often experience burden, which may be coupled with depression. This combination of depression and burden places the care recipient at risk for negative consequences as well.

2.3.3.3 Caregiver strain

Relationship quality is closely associated with caregiver role strain (Archbold et al., 1990). Caregivers with positive relationship quality have less caregiver strain because they are able to find meaning in caregiving and, correspondingly, caregivers with weak relationship quality will experience greater caregiver strain (Archbold et al., 1990). High mutuality in family caregivers is a protective factor for negative caregiving outcomes, such as depression, burden, and resentment (Archbold et al., 1990; Ball et al.,

2010; Kneeshaw, Considine, & Jennings, 1999; Lyons et al., 2009; Tanji et al., 2008; Williamson & Schulz, 1995).

2.3.3.4 Decreased relationship quality

Relationship quality is different for all family caregiving dyads; however, I propose those caregivers affected by compassion fatigue are most likely to have a decreased sense of relationship quality with their family member. In a qualitative study of 11 daughter caregivers, the authors described four of the caregivers as using a dispassionate approach (Donorfio & Sheehan, 2001). The daughters using the dispassionate approach demonstrated decreased or only superficial communication, defined their caregiving role in terms of the tasks, and gave little thought to the future (Donorfio & Sheehan, 2001). The dispassionate approach reported by the researchers presumably demonstrates a decreased relationship quality between caregiver and care recipient. Mutuality, a positive relationship quality (Archbold et al., 1990), is affected by the caregiving experience. In a study of 87 caregivers for family members with cancer, the researchers found that difficult caregiving situations arose from a poor relationship (Schumacher et al., 2008).

2.3.3.5 Termination of caregiving, abuse and neglect

Family members feel guilt when they are not able to care for their loved ones at home (Buhr, Kuchibhatla, & Clipp, 2006; Han et al., 2008). When examining Korean family caregivers, Park et al. (2004) found more than half stated they felt guilty about deciding to place their loved one in an institution. One daughter recollected, "I couldn't sleep for days. Thoughts like why did I do such a thing? Or what would her life be like? Would not let me go to sleep" (Park et al., 2004, p. 351); and another daughter recalled, "Sometimes I wonder how much she must hate me inside for doing this to her. I feel guilty because I feel she's saying 'How could you abandon me here?'" (Park et al.,

2004, p. 351). Family members who need to make this decision often have a difficult time and experience what Park et al. describe as deep sorrow (2004).

Another study exploring nursing home placement by wife and daughter dementia caregivers found an interaction between kinship and role captivity, role overload, and day care use (Cho, Zarit, & Chiriboga, 2009). Role captivity, described as how trapped and constrained the caregiver feels, and role overload, described as overwhelming caregiving demands, were described by the authors to be primary subjective stressors in nursing home placement. This study of 371 caregivers revealed that regardless of relationship, those caregivers with high role captivity placed their family member in nursing homes earlier than caregivers who had low role captivity, while only wives placed their husbands in nursing homes earlier when role overload was high (Cho et al., 2009). This suggests that caregivers who feel trapped and constrained, like caregivers with compassion fatigue who suffer hopelessness and helplessness, are more likely to place a family member in a nursing home earlier than those who do not feel this way (Cho et al., 2009).

Caregiver depression and burden places care recipients at risk physically and emotionally. Thorpe et al. (2006) examined caregiver psychological distress in 1,406 dementia caregivers and found caregiver distress to be significantly negatively related to a care recipient receiving an influenza vaccination. Gainey and Payne (2006) conducted a review of 751 elder abuse cases from Adult Protective Services and found caregiver burden did not correlate with increased abuse, but was associated with increased neglect and exploitation.

People with dementia are not only at risk for neglect, but also at increased risk for physical abuse from the caregiver. In a sample of 417 informal caregivers, Shaffer, Dooley, and Williamson (2007), discovered that as a caregiver feels increasingly

resentful towards the care recipient, he or she is more likely to abuse the care recipient. Pérez-Rojo et al., in a sample of 45 Spanish caregivers from Madrid, demonstrated that the greater a dementia care recipient is dependent upon the caregiver, the less help a caregiver receives, and the more aggressive the dementia patient's behaviors, the more likely the caregiver is to become aggressive and possibly abusive (Pérez-Rojo et al., 2009). Pérez-Rojo et al.'s study did not compare Spanish caregivers to other ethnic groups and thus more research is needed in a more diverse sample. The studies presenting the negative consequences of caregiving generally examined large populations and multiple studies found the same results. While no studies specifically examined the negative effects of compassion fatigue on informal caregivers and care recipients, this is not unexpected because the concept has not been previously defined for this population.

2.4 Conclusions

Compassion fatigue in family caregivers has not been the focus of a primary research study. In this analysis, I have demonstrated that the concept applies to family caregivers. I propose that compassion fatigue in family caregivers may be the combination of hopelessness, helplessness, apathy, and emotional disengagement that occurs after a prolonged exposure to suffering. Compassion fatigue depends upon concern and an empathic response from the caregiver for the care recipient with dementia, and this concern and emotional attachment is the motivation for the caregiver to relieve the suffering. If a caregiver experiences an empathic response, coupled with competing life demands and a lack of satisfaction from caregiving, they may be at risk for compassion fatigue.

Compassion fatigue is a process; it is the end result of a cascade of events that in turn may lead to caregiver depression, increased burden, caregiver strain, and decreased

relationship quality. The consequences of compassion fatigue may also lead to termination of the caregiving relationship through premature admission to a long-term care facility or relinquishing care to another family member or to behaviors of abuse or neglect of the care recipient. Research has shown that caregivers of family members with dementia experience the events that lead formal caregivers towards compassion fatigue: empathic ability and concern, prolonged exposure to perceived suffering, no sense of satisfaction, and competing life demands. Likewise, family caregivers exhibit the likely indicators of compassion fatigue and also endure depression and burden.

By applying the concept of compassion fatigue to family caregivers, I have an enhanced understanding of the caregiving experience. This application suggests the following research questions:

- How does compassion fatigue present in caregivers of a family member with dementia?
- To what extent do caregivers for a family member with dementia experience compassion fatigue? Are the compassion fatigue process and its antecedents and outcomes similar to those of formal caregivers (prior research)?
- How is the nature of the relationship between caregiver and care recipient related to the caregiver's risk for compassion fatigue?
- What instruments are available to measure compassion fatigue in family caregivers, and do these measures demonstrate reliability and validity?
- How can nurses intervene to decrease a caregiver's risk for, or experience of, compassion fatigue and its consequences?

It is important for nurse researchers to investigate this concept to fully understand compassion fatigue and the consequences it may have on the caregiving dyad. If health care professionals know the specific cascade of events leading to

compassion fatigue in the family caregiving population, they may intervene and interrupt this cascade at many points. If the cascade is not interrupted and the caregiver develops compassion fatigue, there may be risk for termination of the caregiving relationship, abuse, or neglect (Schumacher et al., 2006; Taylor et al., 2008). It is possible compassion fatigue is analogous to a syndrome that could include this myriad of indicators and consequences as symptoms of an overarching construct. Future research could explore this possibility.

Knowledge of compassion fatigue in family caregivers will lead to development of interventions to reduce this devastating outcome. Interventions may include anticipatory guidance for caregivers identified at risk for compassion fatigue. Nurses are also able to reduce perceived care recipient suffering through interventions such as medication and behavioral management. Additional interventions may utilize online resources, such as chat groups, as well as phone interventions that fit into the complex lives of caregivers.

3. Compassion Fatigue in at-Home Adult Daughter Dementia Caregivers: A Pilot Study

The over 15 million caregivers for older adults with dementia in the United States provide an estimated 17.5 billion hours of unpaid care, valued over $216 billion (Alzheimer's Association, 2013). Family caregivers are essential to the healthcare system, yet these very caregivers experience negative psychological consequences resulting from providing care, such as depression, anxiety, and stress (Cooper et al., 2008; Ott et al., 2007; Schulz et al., 2008; Schumacher et al., 2006; Simpson & Carter, 2013; Taylor et al., 2008). In addition, family members might feel resentful about the caregiving situation and might also feel helpless and hopeless regarding caregiving (Perry, Dalton, & Edwards, 2010). These feelings might indicate that the caregiver is experiencing compassion fatigue. Researchers and authors have offered many definitions of compassion fatigue, the most common being an adverse consequence of caring for individuals in need, resulting in avoidance and detachment (Adams et al., 2008; Joinson, 1992; Keidel, 2002; Sabo, 2011). Prior research on compassion fatigue has focused on professional health care providers and overlooked filial caregivers.

Therefore, the purpose of this pilot was to analyze secondary data from Project ASSIST to substantiate a need for further study of compassion fatigue in adult daughter caregivers of a parent with dementia. In this secondary analysis of semi-structured interviews with six adult daughter caregivers, I also explored the feasibility of studying compassion fatigue in family caregivers.

3.1 Background

Many definitions of compassion fatigue have appeared in the literature since 1992, when the concept was introduced to the health care community as feelings of anger, inefficacy, apathy, and depression resulting from a caregiver's inability to cope

with devastating stress (Joinson, 1992). Compassion fatigue was first explored in nurses and as other caring professions, such as social work and psychology, later adopted the concept (Figley, 2002a; McHolm, 2006; Sabo, 2006), its definition was adapted to focus on prolonged exposure to suffering as one of its primary causes (Figley, 1995). In the professional caregiver literature, compassion fatigue has an acute onset (Figley, 2002a; Sabo, 2006) and engenders negative emotional responses to caregiving. These responses include helplessness, hopelessness, an inability to be empathic, and a sense of isolation (Adams et al., 2008; Joinson, 1992; McHolm, 2006; Robins et al., 2009).

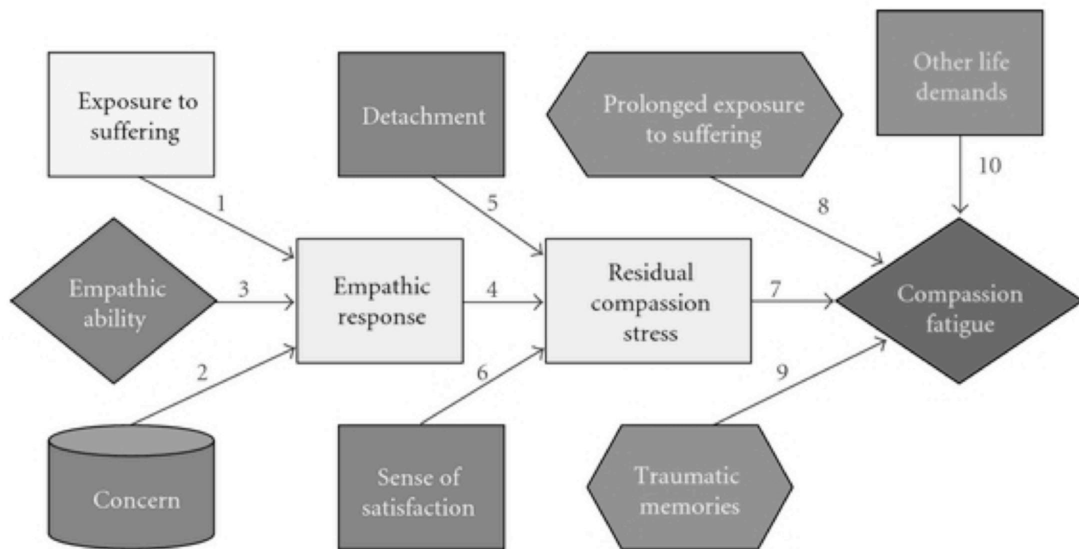


Figure 3: The Compassion Fatigue Process (Figley & Roop, 2006)

As shown in Figure 3, compassion fatigue is a process beginning when a caregiver experiences concern for a person suffering. This creates an empathic response in the caregiver and, when coupled with an inability to detach from the caregiving situation and dissatisfaction with helping the care recipient, a resulting compassion stress. Compassion fatigue then develops from compassion stress when the caregiver is continually exposed to suffering, competing life demands, and traumatic memories

(Figley & Roop, 2006). Importantly, compassion fatigue is dependent upon an exposure to those who are suffering and occurs in caregivers with excessive empathy and self-sacrifice (Lombardo & Eyre, 2011; Sabo, 2011). Compassion fatigue is distinct from depression or burden because it is a combination of responses to caring for those who are suffering; namely the feelings of helplessness, hopelessness, isolation, and an inability to be empathic rather than being singular psychological result. Recurrent themes in the literature suggest the concept of compassion fatigue might be applicable to family caregivers as well as professional health care providers (Day & Anderson, 2011), though little research (Perry et al., 2010; Ward-Griffin et al., 2011) has explored compassion fatigue in family caregivers.

While there is a well-developed body of literature on compassion fatigue in professional health care providers (Bourassa, 2012; Figley, 1995; Hooper et al., 2010; Joinson, 1992; Maiden, Georges, & Connelly, 2011; Najjar et al., 2009; Potter et al., 2013; Sabo, 2006), few studies (Perry et al., 2010; Ward-Griffin et al., 2011) have explored this concept in family caregivers. Perry, Dalton, and Edwards (2010) explored compassion fatigue in family caregivers who assisted in caring for their family member with dementia residing in long-term care settings and validated the presence of compassion fatigue in these family members, as well as factors leading to compassion fatigue (Perry et al., 2010). Caregivers described the caregiving role consuming their lives and also spoke of an overwhelming sadness (Perry et al., 2010). Perry and colleagues (2010) suggest future research on the topic.

In a qualitative study, Ward-Griffin, St-Amant, and Brown (2011), explored compassion fatigue in nurse-daughters assisting in care of an aging parent residing in long-term care. Daughters described love and concern for their parents and intense, prolonged caregiving contributed to compassion fatigue (Ward-Griffin et al., 2011).

Nurse-daughter caregivers also reported feelings of intense guilt and sleep disturbances related to compassion fatigue (Ward-Griffin et al., 2011). These two studies suggest the presence of compassion fatigue in family caregivers for relatives residing in long-term care, but there are no published studies that specifically examine compassion fatigue in caregivers providing care for aging relatives who live at home.

Of family caregivers, adult daughters might be at greatest risk for compassion fatigue due to their perception of care recipient suffering, competing life demands, decreased sense of satisfaction, and inability to detach from the caregiving situation. In a study of 251 caregivers, spousal caregivers were found to have a more positive perception of the care recipient with dementia's quality of life than the adult child caregivers (Conde-Sala et al., 2010). Attachment, empathic ability, and the child caregiver's concern for the care recipient might provide a foundation for development of compassion fatigue (Day & Anderson, 2011). In addition, child caregivers were more likely to be employed and had additional family burdens such as children or dependents (Conde-Sala et al., 2010). Other studies validate the demands on adult children from employment, and include role strain and depressive symptoms for adult child caregivers resulting from work demands (Wang et al., 2011).

An important meta-analysis of 168 studies comparing spouses, adult children, and children-in-law caregivers for older adults, noted significant differences between spouse and adult child caregivers (Pinquart & Sorensen, 2011). Adult children were more likely to be employed, female, and to be caring for older care recipients, but were less likely to reside with the care recipient than spousal caregivers (Pinquart & Sorensen, 2011). Adult children might be at greater risk for compassion fatigue because they are likely exposed to increased suffering due to an older age of care recipient coupled with a decreased perception of quality of life. They also have more demands on their time and

daughter caregivers report a greater number of days with decreased mental health when compared to wives (Simpson & Carter, 2013). Such factors, when combined together, reflect many of the contributing factors of compassion fatigue shown in Figure 3. Little is known, however, about compassion fatigue in family caregivers and the purpose of this secondary analysis was to determine if further research on compassion fatigue in family caregivers is warranted.

3.2 Methods

3.2.1 Project ASSIST

Data for this secondary qualitative content analysis were obtained from semi-structured baseline interviews with caregivers from the Project ASSIST for Chronic Illness Caregivers (Assistance, Support, and Self-health Initiated through Skill Training, NIH R01 NR008285). Project ASSIST was a randomized trail of family caregiver home care skill training, addressing cognitive and behavioral skills for caregivers of older adults with Alzheimer's disease (AD) or Parkinson disease. The aim of the parent study was to determine the results of an intervention designed to decrease depressive symptoms and caregiver burden, and increase caregiver preparedness. Data collectors for the parent study obtained informed consent and collected baseline data. Caregivers were randomly assigned by a sealed envelope process to either the intervention group or the control group (friendly phone call). Data from Project ASSIST has been presented elsewhere (Davis, Gilliss, Deshefy-Longhi, Chestnutt, & Molloy, 2011; Davis, Weaver, & Habermann, 2006; McLennon, Habermann, & Davis, 2010; Shim, Landerman, & Davis, 2011; Shim, Barroso, & Davis, 2012).

A score of 23 or less on the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) was used as care recipient eligibility criteria for the original study; therefore all care recipients with AD had moderate to severe disease. Although

not used in this analysis, data collectors in the original study administered multiple measures, including caregiving burden (Vitaliano, Russo, Young, Becker, & Maiuro, 1991), depressive symptoms (Radloff, 1977), caregiver preparedness, and relationship quality as measured by the Mutuality Scale (Archbold, Stewart, Greenlick, & Harvath, 1992) to all caregiver participants. Data were obtained with permission of the Principle Investigator (PI) and all interviews used for this secondary analysis were de-identified. Institutional Review Board approval was obtained prior to conducting the study.

3.2.2 Semi-structured Interviews

Project ASSIST staff conducted semi-structured interviews with caregivers. To standardize interviews, study staff, comprised of social workers and nurses, received 24 hours of training in the use of an interview guide, and were observed in the conduct of caregiver interviews by a member of the research team or project manager. Samples of audiotaped interviews were reviewed on a monthly basis to insure consistency in the interview process, and interviewers were re-trained as needed. All interviews were conducted in the participants' homes and occurred prior to completion of the quantitative measures. Interviewers began by asking the caregivers to describe three difficult or stressful aspects of caregiving that occurred in the past month. Caregivers were then asked to describe three aspects of caregiving they found to be positive or events that went well in the past month. Interviews were conducted at baseline, 6 months, and 12 months. De-identified baseline interviews were used for the analysis in this study to ensure that participants' responses were not influenced by the ASSIST intervention. The purpose of this pilot study was exploratory to determine if further research on compassion fatigue in family caregivers was warranted, therefore, the longitudinal aspect of the parent study was not applicable to the intent of the secondary analyses.

The aim of this study fits well with secondary data analysis. The nature of the interview questions, asking about their challenges and satisfactions with caregiving, were likely to illicit information about risk factors for compassion fatigue or information on compassion fatigue itself. Secondary analysis as a pilot study allowed the researchers to explore the data for the concepts related to the compassion fatigue model without the steps of data collection and sample selection and focus on the analysis (Szabo & Strang, 1997). Other research studies with caregivers for family members with dementia (Davis et al., 2011; Shim et al., 2012; Szabo & Strang, 1997) have successfully used secondary analysis of qualitative data.

3.2.3 Participant Subsample

Project ASSIST had 187 care dyads, of which 102 were AD caregivers. Of these AD caregivers, 29 were adult daughters (28% of AD caregivers). Baseline interviews of six adult daughter caregivers for older adults with AD were chosen from Project ASSIST for this secondary analysis pilot study. Six participants were selected because the aim was to determine if any contributing factors, outcomes, or indications of compassion fatigue were present in this small subsample and thus, a larger, more detailed study would be justified and meaningful to fully explore the concept of compassion fatigue with a larger sample. Using stratified purposive sampling, participants were chosen to represent caregivers with a range of experience. The 29 adult daughters caring for a parent with AD were rank ordered on their caregiving experience (number of years caring). Two caregivers with little (0 – 2 years), two with moderate (3 – 5 years), and two with considerable caregiving experience (6+ years) were arbitrarily selected based only on their years caring. This wide range of experience was chosen to assure diversity in participant responses, and advances the aim of substantiating the need for a larger study.

To be included in Project ASSIST, caregivers had to be providing care for at least six months and to be included in this secondary analysis, caregivers also had to be daughters caring for a parent with AD. Baseline characteristics of the parent study have been detailed elsewhere (Davis et al., 2011). Demographic data for the subsample is presented in Table 2. In the parent study, 83% of dementia caregivers were women and 75% were White; of the caregivers selected for this analysis, four were White and two were Black. The six participants were all women, aged 54 to 60 and had a mean length of time caregiving of 3.5 years, with 7 years as the longest duration of caregiving. Dementia caregivers in the parent study had a mean age 64.1 and a mean length of time caregiving of 4.5 years.

Table 2: Caregiver Demographic Data

Daughter Caregiver	Age	Race	Years of Education	Years Caregiving
1	59	White	16	6
2	54	Black	13	7
3	59	White	16	0.5
4	56	Black	14	3
5	60	White	16	4
6	54	White	14	1

3.2.4 Data Analysis

In Project ASSIST, caregivers were asked open-ended questions about their challenges and satisfactions with caregiving; audiotaped interviews were transcribed verbatim and verified for accuracy in the parent study. In this secondary analysis, verbatim transcripts of the caregiver interviews were analyzed using qualitative content analysis (Sandelowski, 1995). The analysis focused on the concepts related to the compassion fatigue process. Each interview was read through as a whole for the preliminary analysis. During this first read, key points were underlined and a brief abstract of the interview was written (Sandelowski, 1995). Next, the transcripts were

coded for manifest content (Graneheim & Lundman, 2004; Sandelowski, 1995, 2000). A priori codes based on the model of the compassion fatigue process were first used for any data representing contributing factors, indicators, and outcomes of compassion fatigue; these included exposure to perceived suffering, motivation to respond, inability to detach, empathic response, lack of satisfaction, competing life demands, helplessness, hopelessness, apathy, and emotional disengagement. New codes, such as coping strategies and obligation, were added until all data were coded. All interviews were first coded individually. To enable the visual analysis of the data for themes, each participant's quotes for each code were placed in a matrix with rows for each code and columns for related quotes and a column for comments from the research team. Other column headings were indications of coping and emotional responses and many of the a priori codes related to the compassion fatigue process were incorporated under these columns, particularly the emotional responses column. The six matrices were then combined and the resulting matrix was analyzed to identify themes.

To address credibility, a coding manual (Weber, 1990) was created and agreed upon between the investigator and the PI of the parent ASSIST study. The coding manual included definitions and examples for each code. In addition, both reviewers analyzed all six interviews and discussed the coding until a consensus was reached. Other strategies to maintain rigor were used in the parent study and the secondary data analysis. The coding manual and the matrix, particularly the column with comments from the research team, address the dependability of the study and provide the analytic documentation (Wolf, 2003) for the study. Although the sample size was small, the detailed reporting of findings from the secondary analysis will increase the transferability and other qualitative studies have reported results with similar sample sizes (n=6) (Perry et al., 2010; Tan & Schneider, 2009).

3.3 Results

Four themes emerged from the analysis supporting the possibility that daughter caregivers might be at risk for developing compassion fatigue. The four themes were: (a) uncertainty, (b) doubt, (c) attachment, and (d) strain. These four themes are notably connected to the contributing factors for compassion fatigue, particularly empathic ability and empathic concern, inability to detach, and other life demands. These findings are significant because they suggest for the first time that the family members caring for an older adult at home might be at risk for developing compassion fatigue and provide justification for further research on compassion fatigue in this population.

3.3.1 Uncertainty

The uncertainty theme is related to the adult daughter caregivers feeling unsure when caring for their mothers. Often, their uncertainty was related to AD and the trajectory of illness. Adult daughter caregivers often stated they were uncertain how to respond in a situation and were fearful that something distressing would happen to their mothers if they did not act appropriately. As one caregiver stated when asked about a caregiving challenge, "Knowing when her sugar's going to drop. Being prepared to help her when [it] does. Then, when something happens to her that I don't really know what's happening." Another daughter caregiver explained:

> The fear of the unknown, what's going to happen next, and will I pick up on it quick enough so she's not in danger or has she ever run away. No, but I'm worried about it. And then health wise, too, it's just like when you have little kids and you're the mom trying to keep everybody alive. Well, I'm still doing that.

This same daughter caregiver expressed her fear and described the uncertainty related to caring for a parent with AD:

> I just want to do a good job and I'm afraid I'm going to make a mistake. Say like, oh, well, she's never run off, so she probably never will and I'm in the shower and I come down and I can't find her. And she's out in the middle of the street

> and a car has hit her… This situation is so fluid…sometimes things stay the same for a period of time and you might get used to that, then everything changes.

Another caregiver described the confusion she feels when trying to understand how AD has affected her mother:

> So sometimes I do think that she knows what she's doing or where she is or what's going on with her. And then by the same token, something else will happen and then I'll realize that oh no! So it's a little bit confusing. You don't really know where the truth begins and something else ends or whatever.

3.3.2 Doubt

Other times, caregiving daughters expressed doubt about their ability to meet their parent's needs, feeling a discrepancy between their expectations for themselves as caregivers and the way in which they were actually caring for their mothers. Daughters reported feeling that they were not caring for their mothers the way their mothers deserved. In addition, caregiving daughters tried to prevent their mothers from feeling upset regarding issues related to AD, such as when the mothers did not remember daughters' names. As one daughter stated:

> I just felt like I didn't handle that very well, so that was a real bad thing. That kind of bothered me. And when she first came home from the hospital, not knowing that the head wasn't allowing the body to get up. [Mother] sat in that bathroom all night long.

Another daughter described how she wanted to care for her mother and that she felt she was not doing a good job. She described a situation in which she cooked for her mother and developed negative feelings about herself because she did not feel that she could make her mother happy:

> Not feeling that I'm able to take care of her the way I should be able to take care of her. I took care of [people] in a nursing home. I should be able to do more for her, and I can't. I can't make her happy, walk with her, do what she likes to do. And she's told me I don't have to. But it's hard. She's my mama. And I have to get over that. I couldn't cook dinner right. [I felt] like I was useless and stupid and dumb. I tried not to let her see it. I try to remember that she has Alzheimer's, and it's not her fault.

The previous statement illustrates the concept that the daughters were trying to prevent their mothers from experiencing distress from symptoms of AD. The adult daughter caregivers perceived their mothers' suffering and did not want to increase it. One daughter states:

> I'm more concerned I might say or do something that might upset her. And I don't want to do that. I would do anything to keep her from getting upset or angry. There's a saying that you want to hurt me, that's one thing. But you go after my mother, as my dad would say, "God had better take your soul because your rear end is mine." I will go for the jugular if anyone even thinks about hurting her. She means that much to me.

Another daughter, when recounting a situation in which her mother forgot who she was, described how she handled the situation, "Okay, and so at this point, I'm just sort of walking around like going, 'Okay, try not to say the wrong thing, try not to cry'."

These daughters desired to protect their mothers from any suffering and a caregivers' exposure to perceived suffering is a contributing factor for compassion fatigue.

3.3.3 Attachment

As anticipated, daughters caring for mothers with AD were emotionally attached to their mothers and expressed willingness to care for them. These caregivers also described satisfaction from caregiving. This theme was most evident in the caregiver responses to the interviewer asking the question "What are some of the positive experiences that you've had as a caregiver for your mother?" Caregivers often responded with specific stories. One caregiver told of lying in bed with her mother and enjoying the time with her:

> Oh yeah, this morning. We …crawled in bed together. Just because it made me feel like I was loved. And I was with my mama. And I miss not having her around like she used to be.

Another daughter stated: "Oh, yeah, we have some times we laugh. Sometimes she come back in and be on a, wow, I mean, all the way up. She just be like she's totally back. And we just sit and laugh and cackle." These stories illustrate the relationship between caregiver and care recipient and although the relationship changes, the daughters are still connected with their mothers. A prior positive relationship and emotional attachment motivated the daughters to care for their mothers. As one daughter said, "So then I know what I need to do to care for her. And I feel good about doing that because I know she's taken care of me all my life." Another caregiver articulated this:

> Our values are the same. I mean, she raised me, and she's an excellent mom and my dad was an excellent dad, so I like her so I can say I think it would be harder if you were a caregiver and maybe you didn't have a good relationship with that parent and maybe you really didn't like them and you were doing it because it was the right thing to do and all that, but in her case, I think she deserves it, the best I can do.

Even though the mother-daughter relationship changed, caregiving daughters also felt that their relationship with their mothers was bettered through caregiving: "I've learned how to accept her as a woman. I've learned what it means to really love someone: bad, good, rich, poor, whatever, just know how to get closer to her."

Daughters also told of their mothers' personal histories and past experiences and how this was important in the way they approached caregiving. Many daughters felt their mothers had not had a good life and through caring for their mothers, the daughter caregivers were able to make up for this:

> And knowing that my mother has been the sweetest person in the world. She never said anything bad about anybody. We called her a Pollyanna because she always saw the good side of everything. No matter what it was. If I was going to the doctor and didn't want to [she would say] "Well just be glad you have a doctor to go to."

Another daughter added: "But I just feel like she has never ever had a great life." Daughters were motivated to care for their mothers and in turn received satisfaction

from this. One daughter, however, did not find joy in caregiving, nor did she feel satisfaction from caring for her mother. This daughter, possibly experiencing compassion fatigue, expressed her hopelessness, anger, and frustration saying:

> It upsets me, the disease—the horrible disease. I don't know. When I'm bathing her, I don't have time to think about anything else, to tell you the truth. But when I do think about it, I hate it. I hate that disease. And I don't hate things or people, but I hate that disease. I hate it. And I would do anything if I could help find a cure for it.

The relationship between mothers and adult daughter caregivers likely places the caregivers at risk for compassion fatigue; while at the same time this close emotional relationship provides the motivation for caregivers to care for their mothers. In addition, daughters found satisfaction in caregiving through their attachment to their mothers.

3.3.4 Strain

All of the daughter caregivers described competing life demands, another contributing factor for compassion fatigue. Caregivers' competing demands ranged from husbands and jobs, to church activities and grandchildren. Daughter caregivers had to take time from other activities to care for their mothers and often felt that they were missing out on things. Daughters caring for mothers with AD spoke of how physically tired they were. One daughter fell asleep on her way home from work and got into a car accident:

> That kind of has my rest broken, and when I get to work the next day, I'm just no good, I'll be sleep all day. And I just can't hardly function and for a while when I would be coming home from work, I would actually be sleep, and I would just nod off.

Another daughter described the stress she felt when trying to help her daughter plan a wedding while caring for her mother:

> My daughter got married and I had to help her plan and do showers, and the wedding, and all of these things around my mom. And every time something important happened, my mother would wind up at the doctor or a hospital. It was really, really hard.

This same daughter discussed how difficult it is for her to do all of the things in her life that she would like to when she says, "Juggling my time, taking care of the house here, and my house there, and my job and friends and family. It's just hard to juggle it sometimes."

Daughter caregivers depended on family members to help care for their mothers at times. Often the help was another sibling, and some caregivers shared that they had looked into either adult daycare or long-term care facilities for their mothers. Some caregivers had scheduled breaks from caregiving or activities to help ease some of the caregiving burden; Daughter 1 had weekly "dates" with her husband and Daughter 3 had a standing weekly phone call with her cousin. These coping strategies allowed the daughters to continue caring for their mothers and buffered against developing compassion fatigue.

3.4 Discussion

While this secondary analysis of six interviews did not confirm the presence of compassion fatigue as it has been experienced by professional caregivers, the interviews and statements from the participants suggest that adult daughter caregivers might be at risk for compassion fatigue and thus it warrants further research. This analysis provides evidence for many of the concepts from the model of the compassion fatigue process (Figure 3) leading to a caregiver developing compassion fatigue. Daughter caregivers articulated the contributing factors for compassion fatigue of an exposure to suffering, an inability to detach or attachment, and other life demands.

Adult daughters in this study caring for parents with AD perceived their parent suffering and tried to minimize this suffering. This is consistent with prior research findings that caregivers often perceive the care recipient to be suffering regardless of

how the care recipient reports suffering themselves (Monin, Schulz, Feeney, et al., 2010; Monin, Schulz, Martire, et al., 2010). Closely related to exposure to perceived suffering, the adult daughters in this sample tried to prevent their mothers from experiencing the negative outcomes related to AD. This exposure to suffering and the caregivers' desire to decrease the suffering are the first steps in the process of compassion fatigue.

All participants experienced strain and described competing life demands. Other studies have reported similar results, particularly when participants were adult children caring for a parent with dementia (Conde-Sala et al., 2010; Wang et al., 2011). Strain and other demands often are associated with caregiver employment (Conde-Sala et al., 2010; Wang et al., 2011), and one participant in this secondary analysis described such exhaustion that she fell asleep behind the wheel while returning home from work. When considered in combination with the exposure to perceived suffering and a desire to minimize or alleviate the suffering, these other demands place the caregivers at risk for compassion fatigue. Competing life demands coupled with a prolonged exposure to suffering, the inability to detach, and a lack of satisfaction might allow the caregivers to advance from being at-risk to demonstrating compassion fatigue.

In addition, all participants in the secondary analysis study articulated an attachment to their parent. Attachment and affection for a parent might demonstrate the daughters' inability to detach from the caregiving situation, which in professional caregivers was another factor contributing to development of compassion fatigue. The attachment between a daughter caregivers and the parent, however, might be a protective factor against compassion fatigue. Many caregivers in this study linked their satisfaction with providing care to their relationship with their parent. The daughters interviewed often spoke of attachment in a positive sentiment and it was their motivation to continue caring. A longitudinal study with 116 married or cohabitating

dementia caring dyads, found caregivers with secure attachment had significantly higher levels of well-being then caregivers with insecure attachment (Perren, Schmid, Herrmann, & Wettstein, 2007). Roughly 75% of couples in the study were securely attached (Perren et al., 2007) and although this study did not include adult children, the results illustrate the important effect attachment might have on the caregiver's emotional well-being. Additional, in-depth understanding of the relationship between attachment and the inability to detach would provide more information about the application of compassion fatigue to family caregivers.

While uncertainty and doubt were not contributing factors represented in Figley and Roop's model of the compassion fatigue process (Figley & Roop, 2006), these themes demonstrate the complexity in providing care for a parent with dementia and are not unique to this study. The themes of uncertainty and doubt found in this study are similar to the feelings of inadequacy and powerlessness experienced by nurse-daughters while assisting with care for a parent in long-term care (Ward-Griffin et al., 2011). Based upon these and their other findings, Ward-Griffin and colleagues (2011) concluded nurse-daughters were at risk for compassion fatigue. In another study, Lu and Haase (2009) concluded that family caregivers spouses with mild cognitive impairment, experienced "shock, anger, guilt, frustration, sadness, loneliness, helplessness, and uncertainty" (Lu & Haase, 2009, p. 9). Participants in their study, however, had not been diagnosed with AD as were the care recipients in Project ASSIST.

The findings from our study are similar to other studies (Bandeira et al., 2007; Ott et al., 2007; Papastavrou et al., 2007) of dementia caregivers and describe the difficulty in caring for a family member with AD. Findings from this secondary analysis pilot study are also similar to the two studies exploring compassion fatigue in family caregivers (Perry et al., 2010; Ward-Griffin et al., 2011). Health care providers need to be aware that

family caregivers might be at risk for compassion fatigue, and more research on compassion fatigue in family caregivers is needed to fully understand compassion fatigue as experienced by family caregivers. Future research will allow health care providers to recognize family caregivers who are at particular risk for compassion fatigue. With this knowledge, researchers might develop screening tools to help identify this vulnerable group of caregivers.

Furthermore, once compassion fatigue is recognized and effectively examined in family caregivers, health care providers will be positioned to develop and test interventions. Adult children caregivers represent a rapidly growing segment of the caregiving population and need interventions and assistance because they are suffering negative consequences of caregiving. These interventions might include preventive support for caregivers identified at risk for compassion fatigue. In addition, health care providers can also reduce care recipient suffering through medication or behavioral management, thus reducing the caregiver's sense of perceived suffering. Other interventions might incorporate online resources that would fit into caregivers' complicated schedules.

3.5 Limitations

Although findings from this study contribute to the knowledge base on dementia caregiving and begin to explore an important concept in a new population, there are several limitations. One limitation is that because this was a secondary analysis, the aims and research questions for this study differed from those of the parent study. The intent of this secondary analysis was to substantiate a need for a full-scale study of compassion fatigue in family caregivers. While the investigator was unable to ask questions of participants, the PI for the parent study was involved in the data analysis and was accessible to provide additional information and context about the interviews.

Additionally, the small sample size limits the generalizability of the results to other caregivers for a family member with dementia.

3.6 Conclusion

This study is the first to explore the concept of compassion fatigue among daughters caring for parents with AD at home. The findings demonstrated that these daughters experienced several antecedents of compassion fatigue, and thus appeared to be at risk for developing compassion fatigue. Findings from this study suggest a need for a larger study exploring compassion fatigue and its antecedents and consequences in this population. Future studies should examine compassion fatigue and the negative outcomes associated with it in at risk caregiver populations.

4. Compassion Fatigue in Adult Daughter Caregivers for Parents with Dementia

4.1 Background

Compassion fatigue is a concept that was introduced to the health care community as feelings of anger, inefficacy, apathy, and depression resulting from a caregiver's inability to cope with devastating stress (Joinson, 1992). Compassion fatigue was first observed in nurses and later in other caring professionals such as social workers and psychologists (Figley, 2002a; McHolm, 2006; Sabo, 2006) and the definition was adapted to focus on prolonged exposure to suffering as one of the primary causes (Figley, 1995). In the professional caregiver literature, compassion fatigue was described theoretically to have an acute onset (Figley, 2002a; Sabo, 2006) and engendered negative emotional responses to caregiving such as helplessness, hopelessness, an inability to be empathic, and a sense of isolation (Adams et al., 2008; Joinson, 1992; McHolm, 2006; Robins et al., 2009).

Although compassion fatigue has not been studied in family caregivers providing care at home, their experiences, particularly those of adult daughter caregivers for parents with dementia, appear to create a foundation for developing compassion fatigue. Adult children caregivers represent a rapidly growing segment of the caregiving population and need interventions and assistance when suffering negative consequences of caregiving. From 2004 to 2009, the percentage of adult children caregivers increased from 57% to 62%, and their average age increased from 48 to 51 (Alzheimer's Association, 2009a, 2010). Caregivers for older adults with dementia are often daughters; about 60% of these caregivers are daughters or daughters-in-law (Alzheimer's Association, 2010). For example, one study found 38 of the 51 caregivers (75%) studied were female with an average age of 57 years (Rosa et al., 2004). Studies

have shown that caregivers for people with dementia experience depression, anxiety, and stress (Aguglia et al., 2004; Cooper et al., 2008; Croog et al., 2006; Ott et al., 2007; Rosa et al., 2004; Schumacher et al., 2006; Taylor et al., 2008; Yaffe et al., 2002) and feelings of resentment, helplessness, and hopelessness, in addition to feeling that they have little free time (Hirschfeld, 2003). Caregivers who have these feelings and experiences on top of the emotionally laden filial caregiving relationship might be suffering from compassion fatigue. For this reason, it is important to investigate compassion fatigue in this growing population of caregivers.

According to Figley (2002a), compassion fatigue is a process beginning when a caregiver experiences concern for a person's suffering. This creates an empathic response in the caregiver and, when coupled with an inability to detach from the caregiving situation and dissatisfaction with helping the care recipient, a resulting compassion stress. Compassion fatigue then develops from compassion stress when the caregiver is continually exposed to suffering, competing life demands, and traumatic memories (Figley & Roop, 2006). In this theory, compassion fatigue is dependent upon an exposure to those who are suffering and occurs in caregivers with excessive empathy and self-sacrifice (Lombardo & Eyre, 2011; Sabo, 2011). Compassion fatigue is distinct from depression or burden because it is a combination of responses to caring for those who are suffering; namely the feelings of helplessness, hopelessness, isolation, and an inability to be empathic rather than being a singular psychological result.

Potential outcomes of compassion fatigue might be increased depression, burden and caregiver strain, and a decreased feeling of relationship quality for the caregiver (Braun et al., 2009; Schumacher et al., 2008; Steadman et al., 2007). Compassion fatigue might then lead to the caregiver relinquishing care, such as premature nursing home

admission, and might possibly lead to abuse or neglect (Gainey & Payne, 2006; Pérez-Rojo et al., 2009).

A recent literature review suggested that the concept of compassion fatigue might be applicable to family caregivers (Day & Anderson, 2011). While there is a well-developed body of literature on compassion fatigue in professional health care providers, (Bourassa, 2012; Figley, 1995; Hooper et al., 2010; Joinson, 1992; Maiden et al., 2011; Najjar et al., 2009; Potter et al., 2013; Sabo, 2006), few studies (Perry et al., 2010; Ward-Griffin et al., 2011) have explored this concept in family caregivers. In one qualitative study, Perry, Dalton, and Edwards (2010) explored compassion fatigue in family caregivers who assisted in caring for their family member with dementia residing in long-term care settings and validated the presence of compassion fatigue in these family members, as well as factors leading to compassion fatigue (Perry et al., 2010). Caregivers described the caregiving role consuming their lives and also spoke of an overwhelming sadness (Perry et al., 2010). Perry and colleagues (2010) suggest future research on the topic.

In another qualitative study, Ward-Griffin, St-Amant, and Brown (2011), explored compassion fatigue in nurse-daughters assisting in care of an aging parent residing in long-term care. Daughters described love and concern for their parents and intense, prolonged caregiving contributed to compassion fatigue (Ward-Griffin et al., 2011). Nurse-daughter caregivers also reported feelings of intense guilt and sleep disturbances related to compassion fatigue (Ward-Griffin et al., 2011). These two studies suggest the presence of compassion fatigue in family caregivers for relatives residing in long-term care, but there are no published studies that specifically examine compassion fatigue in caregivers providing care for aging relatives who live at home.

Of family caregivers, adult daughters might be at greatest risk for compassion fatigue due to their perception of care recipient suffering, competing life demands, decreased sense of satisfaction, and inability to detach from the caregiving situation. In a study of 251 caregivers, adult child caregivers were found to have a more negative perception of the care recipient with dementia's quality of life than the spousal caregivers (Conde-Sala et al., 2010). Alzheimer's caregivers also care for longer periods of time than caregivers for other chronic illnesses (Ott et al., 2007); 43% care for one to four years, compared to 33% for other illnesses and 32% care for five years or more, compared to 28% of other caregivers (National Alliance for Caregiving & AARP, 2009). Caring for a parent with dementia was described by one child as "the funeral that never ends" (Meuser & Marwit, 2001, p. 666) and demonstrates a prolonged exposure to perceived suffering.

In addition, child caregivers were more likely to be employed and had additional family burdens such as children or dependents (Conde-Sala et al., 2010). Adult children were more likely to be employed, female, and to be caring for older care recipients, but were less likely to reside with the care recipient than spousal caregivers (Pinquart & Sorensen, 2011). Other studies validate the demands on adult children from employment, and include role strain and depressive symptoms for adult child caregivers resulting from work demands (Wang et al., 2011). Adult daughters have more demands on their time and daughter caregivers report a greater number of days with decreased mental health when compared to spousal caregivers (Simpson & Carter, 2013). Women might not continually be able to successfully fill a number of roles and these overwhelming life demands contribute to a risk for compassion fatigue.

While both children and spouses report feelings of grief, adult children also describe feeling angry and frustrated and spouses describe feeling sad (Meuser &

Marwit, 2001). Adult caregiving daughters are at particular risk for compassion fatigue due to feelings of anger and frustration while caregiving, the quality of the parent-daughter relationship, the multiple roles caregiving daughters have and subsequent role stress from these roles, and the percent of daughters or daughter-in-laws caring for a parent with dementia is higher (Alzheimer's Association, 2010) than any other familial caregiver and therefore daughters are the focus for this study.

Adult daughter caregivers face distinct challenges while caring for parents with dementia and might experience the cascade of events that have led to compassion fatigue in the other populations studied to date. When the specific cascade leading to compassion fatigue is understood in familial caregivers, nurses might intervene and interrupt this process at many points. If the process is not interrupted and the caregiver develops compassion fatigue, there is risk for abuse, neglect, and possible termination of the caregiving relationship (Gainey & Payne, 2006; Pérez-Rojo et al., 2009). Research has demonstrated that individuals cared for at home have lower mortality and morbidity than those in institutional settings, controlling for health status, acute illnesses, and chronic health conditions (Van Houtven & Norton, 2004), and a significant decrease in cost to society (AARP Outreach and Services, 2009; Van Houtven & Norton, 2004). Many religions and cultures value caring for family at home (Clark & Huttlinger, 1998; Han et al., 2008; Park et al., 2004) and it is beneficial for the nursing community to support valuable family caregivers to continue providing safe, effective care in the home.

4.2 Theoretical framework

4.2.1 Theory of compassion fatigue

Figley (2002b) introduced and established a theory of compassion fatigue. This theory describes and explains the relationships between concepts to represent the

psychological phenomenon of compassion fatigue. As shown in Figure 4 (Figley & Roop, 2006), compassion fatigue is a process and the theory has been the foundation for understanding and exploring compassion fatigue in multiple studies with formal caregivers, particularly nurses (Adams et al., 2006; Boscarino et al., 2004; Hooper et al., 2010; Keidel, 2002; Perry et al., 2011; Yoder, 2010).

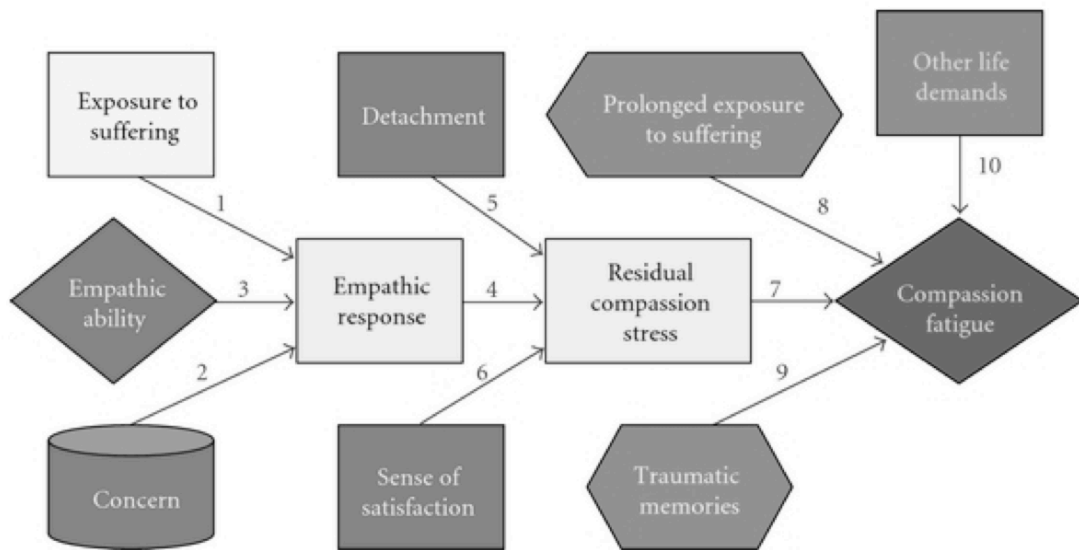


Figure 4: The Compassion Fatigue Process (Figley & Roop, 2006)

The theory of compassion fatigue has generated new hypotheses related to the psychological consequences of providing emotionally demanding care; hypotheses related to secondary traumatic stress (Figley, 1995; Robins et al., 2009; Salston & Figley, 2003) and compassion satisfaction (Hooper et al., 2010; Stamm, 2005; Yoder, 2010) are particularly important developments. Further, new areas of research, such as compassion fatigue in informal caregivers (Day & Anderson, 2011; Perry et al., 2010; Ward-Griffin et al., 2011), emerge from the theory of compassion fatigue. The theory of compassion fatigue is an important tool in understanding the negative consequences of caring for another individual, whether the care provider is a formal or informal

caregiver and the theory of compassion fatigue guided this study. The theoretical model was explored and evidence of the concepts proposed in the model was examined.

4.3 Purpose statement

Therefore, the purpose of this qualitative descriptive study was to explore the concept of compassion fatigue in adult daughter caregivers for parents with dementia and to identify contributing factors and outcomes of compassion fatigue. In this study, compassion fatigue was explored using open-ended interviews with adult daughter caregivers for parents with dementia. This research provided a first detailed description of compassion fatigue in daughter caregivers for parents with dementia.

The specific aim was to explore compassion fatigue and the contributing factors and potential outcomes of compassion fatigue in adult daughter caregivers for parents with dementia and to answer the following research questions:

- What are the characteristics of compassion fatigue described by adult daughter caregivers for parents with dementia?
- What do adult daughter caregivers for parents with dementia describe as contributing factors and outcomes of compassion fatigue?
- How do adult daughter caregivers for parents with dementia vary in characteristics of compassion fatigue and contributing factors and outcomes, and what patterns emerge in this variation?

4.4 Methods

A qualitative descriptive design (Sandelowski, 2000) was used to study compassion fatigue as experienced by adult daughter caregivers. This study included open-ended interviews with adult daughter caregivers for parents with dementia. The relative novelty and limited knowledge development on this concept lent itself well to a qualitative descriptive method as it allowed me to explore the complexity of compassion

fatigue and its contributing factors and outcomes (Barroso, 2010). As the central aim of this study was to develop a detailed description of compassion fatigue, this method, which lacks restrictions from more classical philosophical qualitative approaches, such as ethnography or phenomenology (Artinian, 1988), allowed me to stay closer to the words of participants and to the data and allowed for a rich description of the elements of the concept (Sandelowski, 2000).

4.4.1 Setting and Sample

The dissertation study was based in a three county area of a South Atlantic state with over 430,000 dementia caregivers (Alzheimer's Association, 2013). The area included specific support programs for dementia caregivers, including adult day care centers, support groups, and the state Alzheimer's Association.

The study sample consisted of 18 adult daughter caregivers (17 daughters, 1 daughter-in-law). Caregivers were eligible to participate if they met the inclusion criteria: a) 18 years of age or older, b) the adult daughter, step daughter, or daughter-in-law of a parent with dementia, c) lived with their parent or visit at least once a week to provide care, and d) provide care to their parent to help them take care of themselves. Care was defined to include help with personal needs or household chores, managing parent's finances, arranging for outside services, or visiting regularly to see how their parent was doing. Participant demographic data are presented in Table 3.

Table 3: Participant Demographic Characteristics

Demographic Characteristic	Number of Participants (N=18)
Race/Ethnicity	
White, non-Hispanic	13
White, Hispanic	1
Black	3
Mixed-race American Indian/Black	1
Age range	
<40	1
40-44	1
45-49	2
50-54	2
55-59	7
60-64	2
65+	3
Marital status	
Single, never married	2
Married, long-term partner	14
Divorced	2
Employed outside home	
Yes	9 (6 - 60 hours/week)
No	9
Children living at home	
Yes	5 (aged 4-27)
No	13
Number of years caregiving	
0-2	9
3-5	5
6-9	2
10+	2
Care recipient residing with caregiver	
Yes	8
No	10
Number of hours/week provide care (AVG 60.25)	
2-20	8
21-50	2
51-100	1
101-150	2
151+	3
Not reported	2
Relationship of parent(s) with dementia to caregiver	
Mother	14 (1 mother-in-law)
Father	3
Both parents	1

4.4.2 Sampling plan

Participants were recruited through adult day care centers, self-referral from brochures, snowball sampling (asking existing participants to recruit friends or family), and from monthly support groups held at community sites. Adult day care center directors and social workers from the support programs, geriatric clinics, and the local Alzheimer's Association were encouraged to refer all adult daughter caregivers for a parent with dementia through providing them with the study brochure. Participants were recruited in person from support groups by the principle investigator who attended support groups and invited all interested women to contact her following the support group meetings. Participants were also asked to propose the study to any women they might know also caring for a parent with dementia. When recruitment fell below representative target levels for African Americans, minority providers were approached to help recruit minority caregivers and minority participants were encouraged to refer the study to friends or family. The three counties where the study took place have African American population ranges from 21% to 38.5%, with a state average of 22% according to the latest US Census data.

4.4.3 Consent

At the time of the first telephone contact, the principle investigator explained the study in detail including the interview, the demographic data sheet, and the risks and benefits of the study. Participants were advised that they could stop the interview at any time or withdraw from the study, were informed that information provided was confidential and that digitally recorded interviews would be destroyed when data analysis was completed. When the caregiver agreed, they were screened for inclusion criteria and the principle investigator arranged an in-home visit, or location of the participant's choosing. At this meeting, the study was explained a second time, the

participant signed the consent form, and the principle investigator conducted the first interview and collected demographic data. The Institutional Review Board of the affiliated university approved the protocol.

4.4.4 Attrition/retention strategies

The primary burden of the study was the time to complete the interview. Study participants often benefit from discussing experiences with investigators (Casarett, Crowley, & Hirschman, 2003; Casarett et al., 2001; Lowes & Paul, 2006) and all participants were able to complete the interview and often expressed gratitude for participation in the study. To lessen participation burden, the principle investigator offered to provide supervision of the care recipient during the interview, although no participant requested this. The interview was conducted at a site and time the participant selected to minimize inconvenience; most were conducted in participants' homes and a small number at local cafes. Participants received $25 for participation in the study.

4.4.5 Data collection

4.4.5.1 Open-ended interviews

Open-ended interviews were the central data collection method. Daughter caregivers each participated in a one-time, in-depth interview. All interviews were digitally recorded. Caregivers were asked open-ended questions aimed to elicit descriptions of caregiving experience, compassion fatigue, and any contributing factors or outcomes of compassion fatigue. Field notes were recorded following each interview of impressions of the context and events (detailed example in Appendix A).

The open-ended interview style allowed the daughters to tell their story about caring for their parent. The interviews began with a grand tour type question: "Can you tell me what your experience has been like caring for your parent?" This allowed the

woman to reflect on her feelings as a caregiver and provide an overall depiction of her caregiving experience. Additional questions were asked to illicit information about the contributing factors for compassion fatigue of exposure to suffering, empathic ability, and empathic concern. These questions included, "In what ways do you think your mother/father is suffering?" and "How often do you think about what your mother/father is going through?" Other questions were asked to address detachment and sense of satisfaction and included, "What brings you pleasure in caring for your mother/father?" and "Do you ever feel the need to distance yourself?"

Questions to explore the concept of compassion fatigue further included questions about helplessness, hopeless, apathy, and disengagement. "Do you feel helpless in this situation?", "Do you feel less hopeful about the future?", and "How has your concern changed over the course of caring for your mother/father?"

To address outcomes of compassion fatigue, caregivers were asked "What has been the impact of caring for your parent on your time/ability to get out/friendships/feelings?", "Do you feel that you have difficulty in performing your role as a caregiver?", and "Do you feel depressed?" To address relationship quality between the caregiver and their parent, caregivers were asked first to describe their relationship with their parent before they became a caregiver and were then asked how they felt this relationship had changed.

Appendix B includes the interview guide. Interviews lasted from 55 minutes to 1 hour 48 minutes, with most interviews close to 1 hour 15 minutes. Following the interview, all caregivers received a handout with resources for dementia caregivers, including counselors knowledgeable about dementia and local support groups (Appendix C).

4.4.5.2 Subject characteristics

Data on age, race and ethnicity, occupation, marital status, years of caregiving, number and ages of children, and any other individuals cared for were obtained by self-report on a demographic data sheet (Appendix D). These data were used to describe the sample and to help answer the research question about variation in characteristics of compassion fatigue and the patterns that emerged in the variation. Caregivers completed this sheet prior to beginning the interview.

4.4.6 Data preparation

A professional transcriptionist transcribed the interviews verbatim into word processing files for analysis. I proofed the transcriptions to ensure accuracy (Richards & Morse, 2007) and recordings were kept until data analysis was completed. All transcripts were analyzed in ATLAS.ti. To ensure that confidentiality was maintained, each caregiver was assigned an identification number. The transcribed interviews used this coding scheme to protect the confidentiality of the participants. Other identifying detail was removed or masked during proofing of the transcripts. The list of names and transcribed interviews were kept electronically on a secure server in a separate location. All demographic data were entered into Microsoft Excel after the data was checked for accuracy and completeness. All data were kept electronically on a secure server at the affiliated university.

4.4.7 Data analysis

The overall goal of the analysis was to describe compassion fatigue experienced by adult daughter caregivers and to explore contributing factors and outcomes of compassion fatigue. The analysis addressed the a priori concepts related to the compassion fatigue process and interviews were analyzed using a qualitative content analysis technique (Sandelowski, 1995). The transcripts were coded for manifest

content (Graneheim & Lundman, 2004; Sandelowski, 1995, 2000) using a priori codes based on the model of the compassion fatigue process. All data representing the model's concepts, contributing factors, indicators, and outcomes of compassion fatigue, were coded first; these included relationship before caregiving, exposure to perceived suffering, empathic response, lack of satisfaction, competing life demands, helplessness, hopelessness, apathy, and emotional disengagement. Then, using latent coding, or content analysis involving interpretation of the data (Bernard & Ryan, 2010), additional codes were created. Latent coding allowed me to consider the context and meaning and identify themes or constructs, as compared to manifest analysis where visible or intended meaning of words and phrases were coded with a priori codes (Bernard & Ryan, 2010). Using latent coding, new codes, such as obligation, family support, and validation were added until all data were coded. As new codes were created during later interviews, preceding interviews were reread and coded for data related to the additional codes. An example of the codebook is found in Appendix E.

Each transcript was analyzed in this way as a whole before it was compared with other data. Interview questions for later participants were expanded when significant new topics appeared during data analysis, such as financial burden or physical contact with a parent.

Once all the data were coded for latent content, related codes were grouped together and then all data related to compassion fatigue were explored visually using the network view of the ATLAS.ti software (Friese, 2012). Appendix F is an example of the network view.

Memos within the software were written to record additional thoughts during the analysis process. A second researcher, with expertise in qualitative analysis, read and coded the first two transcripts and more than 10% of the remaining transcripts.

When there was a dispute, it was discussed until agreement was reached. In addition, a third researcher, with expertise in family caregiving, read two transcripts in their entirety and provided feedback and expressed agreement with the coding.

4.4.8 Methods to optimize validity

The interpretative approach (Denzin & Lincoln, 2011) used in this study often draws concerns for a lack of "scientific adequacy" (Sandelowski, 1986, p. 27). Nurse researchers must undertake specific strategies in order to assure rigor and the scientific adequacy of qualitative research (Sandelowski, 1986). Rigor in qualitative analysis is also termed trustworthiness (Lincoln & Guba, 1985). Trustworthiness might be divided into four criteria: credibility, transferability, dependability, and confirmability, each with their own strategies to maintain the rigor of the qualitative research. Credibility is the criterion to evaluate the "truth value of qualitative research" (Sandelowski, 1986, p. 30). The second criterion, transferability, is the applicability or generalizability of findings to other contexts (Lincoln & Guba, 1985; Sandelowski, 1986). Dependability, the third criterion for rigor, is also the auditability or reliability of the qualitative data and analysis (Lincoln & Guba, 1985; Sandelowski, 1986). The final criterion for rigor is confirmability, or the neutrality of the research (Lincoln & Guba, 1985; Sandelowski, 1986). Together, these four criteria assure rigor and Table 4 details how these strategies have been employed in this study.

Table 4: Strategies to Assure Rigor

Criteria	Definition	Strategies Employed
Credibility	Evaluate the "truth value of qualitative research" (Sandelowski, 1986, p. 30)	• Extended contact with daughters caring for parents with dementia • Pilot interviews • 50 observational hours in a clinic that provides cognitive and psychiatric evaluation and treatment, particularly for older adults with dementia • Participation in monthly support group for caregivers of family members with dementia • Peer debriefing: participation in Qualitative Analysis elective • Two classmates, one of whom is naïve to dissertation topic, and the faculty member, read transcripts and coding and provided feedback • Weekly meetings with mentor
Transferability	Applicability or generalizability of findings to other contexts (Lincoln & Guba, 1985; Sandelowski, 1986)	• Present detailed findings • Report sampling technique and describe the population of caregivers interviewed • Ensure contextual information when presenting data • Provide illustrative, representative quotes from participants: allowing others to read the exact words spoken by participants
Dependability	Auditability or reliability of the qualitative data and analysis (Lincoln & Guba, 1985; Sandelowski, 1986)	• Field notes completed after the interview • Methodological documentation (all versions of study protocols, all interview guides, any changes to study personnel, and consent forms) found partly on the IRB website • IRB website with a history of study activity, including amendments submitted and details the reasons many of these changes were made • Analytic memos addressing changes made to the study • Codebook • Second researcher, with expertise in qualitative analysis, read and coded the first two transcripts and more than 10%of the remaining transcripts

Criteria	Definition	Strategies Employed
Confirmability	Neutrality of the research (Lincoln & Guba, 1985; Sandelowski, 1986)	• Personal response documentation • Participants lead during the interviews: less influence on what the participants said and how they shared their experiences • Report detailed description of the methods used • Link conclusions to the data

4.5 Findings

The findings are organized and presented according to the research questions guiding the study and are anchored to the model of compassion fatigue (Figure 4). Table 5 summarized the findings for each model concept, definition, and exemplar quotes.

Table 5: Concept, Definition, and Exemplar Quotes

Concept	Definition	Exemplar Quotes
Helplessness	Feeling that the caregiver does not have the power to act	There is nothing I can do. I mean, I went to her doctor who I know he is a nice doctor, but I feel like I have had to practically almost yell at him a couple times to do something. But I feel like there are things that she can do, like exercise and when this happened I bought her some magazines on some exercises she can do at the house. I bought her puzzles that she could do, everything stimulating that she could do. None of it. So it's like mom. I even went over there a couple of times to do puzzles with her and she did them then and then afterwards she never touched them again. And then say, I do feel helpless. There is nothing, I guess, that can be done for her.

Concept	Definition	Exemplar Quotes
Hopelessness	Feeling the impossibility of a desire to be fulfilled	I guess it does in a way, because I mean there's nothing you can do… I can't control anything that's going to happen. (crying) I don't know why I'm getting emotional. And I think, you asked if it had gotten harder, I think what's gotten harder is that you don't really see light at the end of the tunnel. I think that the challenge is that it just doesn't end. I think with a child, and you expect you're always going to take care of your child… so you know you have that expectation that they're going to leave school, high school, and go off to college, and so you're learning to let go, whereas with Mother it's like now I have a kid that's come back home to live that I'm responsible for, and it's one that I'm always going to be responsible for. She's not going to grow up and go away.
Disengagement	Extent caregiver can distance herself from the suffering. Conscious, rational effort to recognize that she must "let go" of thoughts, feelings, sensations associated with parent to live own life. (Figley, 2002a)	I mean I could compartmentalize that. As a daughter, my mother bamboozled me and frustrated me so much for so many years that as a daughter it was difficult to see her in this situation and know what to do because I knew she wouldn't want me to do it. But if I looked at her as my patient I knew what to do. I mean immediately I knew what to do, so that was very helpful, very helpful to me.
Exposure to suffering	Experiencing the suffering of the parent through direct exposure	I honestly do kind of feel like he is suffering because I know that on a good day he knows where he is and he knows that he can't remember and for somebody like him who is always in charge of everything, I think that would be hell on earth.
Empathic ability	Aptitude to notice the suffering of parent (Figley, 2002a)	I think about what's it like for her every time I see her and times in between as well. Every time I think about her I think about what it's like for her. Because it's impossible for me to imagine myself without my mind. It's the part of me that I most identify with, which it is just impossible to imagine losing it.

Concept	Definition	Exemplar Quotes
Empathic concern	Motivation to respond when parent is in need (Figley, 2002a)	So pretty soon after that they said "you need to go ahead and probably move her to Current Home". And so we did. And I was there a lot because I was afraid she was going to be upset by not being able to have her freedom and go outside and she really wasn't.
Empathic response	Effort exerted to understand the parent's thoughts, emotions, and actions with the aim of empathically responding. Caregiver may experience negative emotions (ex. fear, anger) (Figley, 2002a)	Now he just repeats the same sort of thing, "thank you for taking care of me, thank you for taking care of all this stuff", like he realizes that somebody is taking care of business and he knows that he can't. And I know it's a horrible way for him to live, being the person he is, to not be in control. And he knows, on a good day, that he is in crazy town cause it is crazy over there. And I feel bad about that. I wish he could be somewhere where everybody else was in good shape and it wasn't so frustrating to have people around him repeating and people around him doing these behaviors that are repetitive. I mean, it will drive you crazy real quick. So, it's not really an atmosphere conducive to improving but sometimes he just doesn't get up. He sleeps, certain weeks, he just sleeps every day. And I don't blame him because I think his dream world is much happier than his regular world because what is he gonna do? Meals and TV, meals and TV. That's not a life. And he can't really do a lot of things.
Protection	Wants to protect parent from knowing they have dementia, from physical harm, from humiliation, or what other people might do or think. Caregiver wants parent to not have to worry about life and dementia.	But she doesn't do that to me. Of course I don't give her any cause to either. I know how to deal with her. I can do it. And I had to learn little by little over actually the first few months because I didn't have that relationship with her. I have learned to be the nice person that she can smile at and is glad to see. So it is sort of play acting too… I do like her not being mad and critical of me. I like that and I don't think she needs to be angered. Neither one of us needs that. I just like to keep things a calm and easy as I can.
Relationship before caregiving	Describing what the relationship was like with the parent before caregiver became the primary caregiver	Oh, yeah, it was not perfect. It was never perfect. I guess no relationships are. But it was undoubtedly undergirded by a very resilient sturdy love that we both knew was there.

Concept	Definition	Exemplar Quotes
Obligation	Feeling of responsibility to act or do something because of what the parent did for them in the past. Strong sense of responsibility to care as the child	Well, it's just a necessity and it just is the way it is. I am an only child. Who else is going to do it? I really don't think about that much one way or another.
Sense of satisfaction	Satisfaction with efforts to help parent, sense of achievement, feelings of fulfillment and contentment from caring.	I mean when I go there even if she doesn't need anything. Like if we are sitting outside and it's not too hot and she will fall asleep because she loves to be out in the sun and I helped somebody else. It's like whenever I go there I always feel useful. It's like that's a place where I feel like whatever I do for somebody is really needed… and it's really rewarding because I feel like I've accomplished something. Even if nobody remembers that I did it. So it is personally rewarding for me to go over there.
Other life demands	Things that demand attention (ex. illness, changes in life style, social status, professional/personal responsibilities)	I feel like I'm a lot of places… So I began to be very involved in my temple and before I knew it I had a lot of different jobs there. I don't get paid for them. Well I teach there, so I get paid for teaching. But it doesn't really count. But, so I have many responsibilities there. I joined a book group too. And I can do things like this if I need to. What else? It feels like there is a lot of stuff because I'm always somehow. I'm involved in a couple of interfaith groups so I plan events and facilitate events, interfaith events. So, before I know it, the day is over.
Traumatic memories	Memories that trigger symptoms of PTSD, depression, anxiety, cause an emotional reaction, provoked by types of experiences with a connection to traumatic events experienced by caregiver. (Figley, 2002a)	You never know what's going to happen. And like I said, I work at Hospital, so every time I hear "code stroke, ETA ten minutes," I'm like "is my phone going to ring?" I do, I sit there and wait for my phone to ring just thinking it might be her, because the first time they called the code stroke right before my phone rang and she was on the way in, and by the time I got up to the emergency room she was there, so that's kind of crazy. I don't know if I'll get past that.

Concept	Definition	Exemplar Quotes
Depression	Depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentrations – in life – not specific to caregiving	I think sometimes I am almost, almost there… "I said, oh gosh, am I getting depressed?"… Sometimes if you sit there and think about it enough, you kind of dwell in it, and I am not the type of person to do that, kind of dwelling, self-pity kind of thing. You just have to move on.
Burden	Alterations in caregiver's emotional and physical health, which can occur when care demands outweigh available resources – activities/load to carry – effect of burden on caregiver – not burden itself (Given et al., 1992)	Sad as that all was and as stressful as it was going there every day, it was even more stressful going home. It gave us a much-needed break and made me realize how stressful it is to be the primary and sole caregiver. Just me. And it was nice to have our house back.
Caregiver strain	Felt difficulty in performing the caregiver role (Archbold et al., 1990)	Taking care of her? It's harder than I expected it to be. When I first got her, there was nothing. She could take care of herself for the most part. I mean she had some lapses in memory, but she could take care of herself. Bathed and everything. But now, she can't do anything. Now she can't bathe herself, can't dress herself. She barely feeds herself. And it's a lot harder than I expected.
Change in relationship quality	Change in intimacy, agreement, and independence, change in love and affection, shared pleasurable activities, shared values and reciprocity (Archbold et al., 1990)	I mean I can't think of anything that I do with her that I used to would do, even when, before she had that stroke in September I could, we could go to the mall… So now there's nothing, we can't even go shopping. Or talk about, she used to tell me about her friends, "so and so called and she's doing this or that." We really can't do anything and sometimes, and then because she has this wine, I don't really like to drink wine at two o'clock in the afternoon, but I have just because I thought, "well we're going to put it in a wine glass instead of the little cups like they use to measure out other stuff in out there" and she doesn't even like know that she is having a nice glass of wine and we are having wine together, so there's not anything that's the same about our relationship.

Concept	Definition	Exemplar Quotes
Support	Sources of support for caregiver that help her continue to care for parent	So my brother and sister and I of course had to figure out what to do and decided, looked around at places and in brother's [City] and decided on [Home] because it was near work. It wasn't too far from work and being right there on highway my brother can come from [City], he works at [Company] and my sister could come, so it was kind of a central area. And we liked the place so she moved in there.

4.5.1 What are the characteristics of compassion fatigue described by adult daughter caregivers for parents with dementia?

Adult daughter caregivers in the study described many of the characteristics of compassion fatigue previously identified in formal caregivers. In particular, daughters experienced helplessness and hopelessness, and to a lesser degree, disengagement. There were adult daughter caregivers who denied feelings of compassion fatigue and these daughters often described support from other family members or faith as the reason they were able to feel capable or had hope. Apathy, defined as a lack of interest or concern regarding caregiving, is a characteristic of compassion fatigue that was present in formal caregivers, but no caregivers in this study expressed feelings of apathy. These findings about the concepts of compassion fatigue are detailed below.

4.5.1.1 Helplessness

Caregivers in the study described feelings of helplessness, defined as feeling that they did not have the power to act. Caregivers spoke of three kinds of helplessness: 1) feeling that there was nothing they could do to make their parent better or improve their parent's dementia, 2) feeling that the healthcare system was inadequate and incompetent and that they were not able to do anything to change the system, and 3) feeling that they were not able to make acceptable choices. Some women did not express feeling helpless and explained that they felt supported by other family members or that they were competent in the situation.

Caregivers described feelings of helplessness about being unable to change the course of dementia. Caregivers often said they felt that there was nothing they could do to help their parent and that their parent would continue to decline. Daughters felt that they tried to see to their parent's medical needs and did things to help their parent remain engaged in their life, but their parents continued to have falls and were decreasingly able to interact with the world. As one daughter stated when asked if she felt helpless:

> I feel like I've done all that I can possibly do to take care of them as far as seeing doctors, making sure all of their medical needs are cared for. Even though I've done all that I … can possibly do, things still happen—like my mom falls and breaks her hip… I don't expect that they're gonna get probably any better than they are now. And I do realize that it's a degenerative kind of thing.

Other daughters described feeling that the healthcare system was inadequate and that they were not able to do anything to change the system. Many of the women expressing these feelings were dealing with a parent(s) in a long-term care facility. Caregivers described feeling as though they had to be their parent's voice because their parent was unable to speak up for himself or herself. Caregivers recounted times when they would talk to the staff at the long-term care facility about what their parent would like, but felt as though the staff would not, or could not, do things to accommodate these preferences. One daughter described how she asked that her mother be placed at a dining table with other residents who could converse, but it did not happen. She described feeling helpless because she would make requests or share ideas with the staff, yet nothing would change. Similarly, daughters felt there were rules or regulations in the long-term care facility that did not make sense or cost her extra money. Many daughters spoke of the challenges in obtaining the right prescriptions for their parent, or having the right doctor to visit, and often described feelings of confusion and inaccuracy related the charges and fees from the long-term care facility. They explained that they would ask facility management questions about why the charges were increasing and

would tell management they did not agree with the explanation, but the charges would remain. Daughters did not feel like they could move their parent elsewhere because they would encounter the same thing in another long-term care facility and were sometimes fearful that speaking up would cause their parent to be treated poorly out of retribution. One daughter described her frustration, "And nobody saw her fall, nobody got her up off the floor… There's not a lot of monitoring. Supposedly the number for the [staffing] ratio is within State standards. Nobody ever sees anything and people fall a lot."

Daughters also described feeling helpless when they were faced with a decision to make, but felt they were not able to make an acceptable choice because of limited options. Daughters expressed feeling torn when deciding between caring for their parent and spending time with their spouse or partner. They described feelings of guilt for being away from their spouse when they were with their parent, while at the same time feeling guilty when they were with their parent and described chronically feeling that they did not spend enough time with their parent. Caregivers had these feelings even when they noted that their parent would not remember the visit or acknowledge the time the caregiver spent providing care. As one caregiver stated, she felt helpless trying to decide whether to continue caring for her mother at home or placing her in a long-term care setting. This daughter felt there was no choice that would have a good outcome for everyone; keeping her mother at home was having a negative impact on her life, yet she wanted her mother to be well-cared in an affordable setting. She said:

> I feel torn; I have a responsibility to myself. I have a responsibility to [spouse] and to our relationship and I feel the responsibility to seeing that she [mother] gets good care. Where I feel torn is trying to determine where the end point is. I feel that it is coming because… it has had a significant impact on my life and my ability to go out and do other things and my activities. It has really hemmed in my life…I am trying to figure out how long she will live, how much money we have…

Women who did not describe feelings of helplessness often stated they felt supported, particularly by other family members, or through choosing things that they could actively do in order to feel a sense of control. Caregivers described doing things for their parents, such as continuing to do their parents' laundry, because that was something they could control in the situation and caregivers described feeling a sense of purpose from carrying out these activities. Other family often helped out and provided support to caregivers and many daughters cited family support as a reason they did not feel helpless, saying they felt they had options and could reach out when needed. As one daughter described:

> No, I don't think I would say I ever felt helpless. I know that I have my brothers and sisters out there and that I can ask and I know that my immediate family would always step up to the plate. So, no, I wouldn't say I ever feel helpless.

4.5.1.2 Hopelessness

Adult daughter caregivers also described feelings of hopelessness, a feeling that it was impossible for their desires to be fulfilled. Women who expressed feelings of hopelessness described their desire for their parent to have a different quality of life, but felt that this would not happen because their parent would never get better. Daughters also described wanting to be free of responsibility for their parent, while knowing they would continue to have this responsibility until their parent died. Caregivers realized dementia was a progressive, degenerative disease and that their parent would continue to decline. As one daughter described:

> There's nothing you can do… I can't control anything that's going to happen. (crying)… I think what's gotten harder is that you don't really see light at the end of the tunnel. I think that the challenge is that it just doesn't end…with Mother, it's like now I have a kid that's come back home to live that I'm responsible for. It's one that I'm always going to be responsible for. She's not going to grow up and go away.

Not all women described feeling hopeless and caregivers who did not express hopelessness often found hope through their faith or support of other people.

Caregivers' faith and support allowed them to feel that there was a way for their desires to be fulfilled. As one daughter answered when asked if she felt hopeless:

> No. I think my faith keeps me from that. I don't think I'd ever feel hopeless. I definitely feel sad and down and burdened and that kind of thing but no, not ever hopeless. I'd like to think that I see it more as a trial [and] an opportunity for growth.

4.5.1.3 Disengagement

Daughter caregivers described feelings of disengagement, defined as the extent the caregiver could distance herself from her parent's suffering and the caregiver's conscious recognition of "letting go" of thoughts, feelings, and sensations associated with their parent in order to live their own life. Caregivers described things they did to distance themselves from their parent at various times, such as limiting the time spent with their parent or compartmentalizing their caregiving. Caregivers often described changes in their relationship with their parent when discussing ways they disengaged. Caregivers described disengagement as a temporary feeling and even when caregivers expressed feeling this way, all daughters continued to be involved in caring for their parent. One daughter describes this balance, stating:

> You can only be around that so much. I think the hardest thing for me is that I see a lot of myself in him, so I think part of the reason I don't go more often is because I get depressed fairly easily. I have to watch myself and … I'm trying to protect my own psyche because I really could see myself ending up like him, maybe. So that's also part of it. I'm kind of trying to stay separate. But, believe me, if something happens, I'm there.

Daughters told of they now were decreasing the time they spent with their parent because there was less reciprocation during interactions. As one caregiver described, "I don't try to interact with her as much as I did because she'll start to say something and then she'll just stop in the middle of a sentence… so there's not really any conversation."

Disengagement was described as a way for daughters to continue caring for their parent. They were able to acknowledge their feelings and actively did things that

separated caregiving from other aspects of their lives. Some daughters described having to "put on another face" in order to care, or viewing their parent as a patient at times.

4.5.2 What do adult daughter caregivers for parents with dementia describe as contributing factors and outcomes of compassion fatigue?

Adult daughter caregivers were asked questions about factors found to contribute to compassion fatigue in formal caregivers. These contributing factors, taken from the model of compassion fatigue, included an exposure to suffering, a relationship with the care recipient, empathic concern and empathic response, sense of satisfaction, other life demands, and traumatic memories. Caregivers validated many of the contributing factors and also spoke of other caregiving challenges unique to family caregivers that might contribute to compassion fatigue in this population. In addition to the established contributing factors, daughters in this study described facing a steep learning curve to caring for a parent with dementia and a health care system that did not always seem to provide adequate care for their parent. Also unique to family caregiving, daughter expressed a sense of obligation to their parent. These feelings of obligation were often described as the reason the caregiver began caring for their parent and caregivers stated it was one of the reasons they remained involved with caring for their parent. Similarly, caregivers described a desire to protect their parent; this empathic response was another reason described by daughter caregivers for why they were able to continue providing care for their parent.

Possible outcomes of compassion fatigue that were explored with family caregivers in this study, based upon the literature review, included depression, a change in relationship quality, burden, and caregiver strain. Caregivers in this study particularly described a change in their relationship with their parent and also feelings

of caregiver strain. In addition, these daughters discussed feelings of sadness for the loss of relationship with their parent and spoke of anticipating the loss of their parent.

4.5.2.1 Contributing factors for compassion fatigue

4.5.2.1.1 Exposure to suffering

Adult daughter caregivers described three types of suffering in their parents: 1) physical suffering, 2) psychological suffering, and 3) existential suffering. Some daughters were unsure if their parent was suffering, and these daughters often considered only physical aspects of suffering. Physical suffering included physical signs and symptoms such as pain or lack of appetite. Daughters who described physical suffering spoke of their parents falling and having broken bones or bruises.

Psychological suffering was defined to include the parent feeling a lack of control, depressed, or anxious. Daughters described their parent's psychological suffering and had the sense that their parent was aware of his or her declining mental status. As one daughter said:

> He realizes that somebody is taking care of business and he knows that he can't. I know it's a horrible way for him to live, being the person he is, to not be in control. He knows, on a good day, that he is in crazy town cause it is crazy over there. I feel bad about that. I wish he [was in different setting in which] everybody else was in good shape and it wasn't so frustrating to have people repeating and people these behaviors that are repetitive.

Daughters described feeling their parents were experiencing existential suffering, defined as despair and a loss of meaning and purpose in life. They felt that their parent did not have meaning in their life or that their parent would be upset if they knew what his or her life was like. As one daughter described:

> So he has been living all these years day to day with no purpose. Nothing that he wants to do, literally, he will tell you. If you say, "Is there anything you want to do, dad, is there anywhere you want to go? Come on, we'll hop on a plane," Anything. There is nothing that he wants in life. There is nothing that he can think of that would make his day better or anything. There is just nothing. That is a long time to live with no purpose and no fun and no whatever.

In response to existential suffering, some daughters expressed feelings that they wished their parent could die, which is the only thing that could relieve their suffering. The daughters were aware they would feel a loss when their parent died, but they would also feel a sense of relief for their parent. A daughter explained this feeling stating, "It may sound bad, but I think it'll be a relief. I mean not only giving up the responsibility, but I just feel like she doesn't have a life. (crying) She's limited, and you just don't want that to go on forever."

4.5.2.1.2 Empathic ability, empathic concern, and protection

As described above, the daughters who were exposed to suffering described a desire to relieve their parents' suffering. Caregivers expressed an empathic ability and concern, and an empathic response to the situation. An empathic ability was defined as the caregiver's aptitude to notice suffering of their parent, whereas empathic concern was defined as the motivation to respond when their parent was in need. The caregiver's empathic response was the effort exerted by the caregiver to understand the parent's thoughts, emotions, and actions with the aim of empathically responding. Daughters responded to their parents' needs or declining mental status through changing the parents' situation or environment and often changing their own expectations to what their parent could do. Many caregivers described wanting to "set them up for success." As one daughter described:

> I have a cousin who every time she comes to see my mother, which blessedly is not often, will say, "Do you know who I am?" Well, what's the point of asking that? If she does, she is going to be insulted by your asking. And if she doesn't, it's just going to show her that she doesn't know something. So I form the conversation so she succeeds. That's just part of my job. So our visits are very fine. Nobody gets upset.

Daughters talked about wanting to protect their parent from negative experiences and prevent their parent from knowing they had dementia. In addition, caregivers wanted their parents to have an easy life and for things to go smoothly for their parents. One caregiver explained how she did not share everything going on in her

life with her mother anymore. She did not want her mother to worry about anything and instead only told her certain things that were going on in her life. As she described:

> I don't want to ever cause my mom any worry, so even though I could probably tell her things and they'd be gone the next minute… I just would never want to give her any cause for worry. I want her to live in that little bubble of everything is rosy.

4.5.2.1.3 Pre-caregiving relationship quality

The caregiver's previous relationship with their parent was the reason many daughters described for responding to their parents' suffering. In addition, daughters talked about the quality of the previous relationship as the basis for the entire caregiving experience. Previous relationship quality was described by the daughters in three different ways, 1) positive, loving pre-caregiving relationship, 2) negative, often abusive pre-caregiving relationship, or 3) neutral – neither extremely positive nor negative: the caregiver was the child and their parent was the parent.

Daughters who described a positive relationship with their parent before caregiving said they found a sense of satisfaction in caregiving because of this relationship. One daughter said, "Oh, she was an awesome mom. She stayed at home all the time. She is still an inspiration. She is constantly counting her blessings and reminding me and she is so selfless that I'm still learning." This daughter continued, when asked if she thought she would always care for her mother, "I think she'll always be a number one priority… the history alone keeps me motivated and wanting to see her and make sure everything is going fine in her world." Often daughters were not able to articulate exactly why they continued to care for their parent, other than to say, "it's my mom" and share a feeling of love for their parent. When asked why she continued to care for her mother, one daughter responded, "Because I love her, she is my mom and I know she loves me." Another daughter said, "She's my mom and she's my mom that I have to take care of…that doesn't change the way I feel about her. I love her. I want to make sure she's taken care of the best I can."

Daughters with neutral or negative pre-caregiving relationships with their parents also spoke of the parent-child relationship as a motivating factor for caring for their parent. A daughter with a negative relationship shared:

> I was never close to my mom. My mother was very much a manipulator; she played on your sympathies to get what she wanted… As a result I never had a close relationship with her, but still this is my mom. I will take care of my mom. That is an obligation that I feel as I will take care of my child. I feel very strongly… there are some things are the norm, or they should be the norm, and that just to me taking care of your family falls into that category. It is not an option.

4.5.2.1.4 Obligation

The sense of obligation, defined as a feeling of responsibility to act or do something because of what the parent did for them in the past and because they were their parent's child, came through in many of the interviews with daughter caregivers. When asked why she cared for her mother at home, one daughter responded, "It is what it is. I mean, you got to take care of your parents. Can't leave it for somebody else to do. Don't want to leave it for somebody else to do." She continued, "And I know it's something that's got to be done. It's got to be done, so I've got to do it. I just push through and just pray that Lord gives me patience." Echoing this, another caregiver states, "I think part of my desire to take care of her is probably patterned after seeing my mom and dad take care of their parents. I don't think that it's wrong for anybody to feel they need to put their loved one in a facility, and like I said it may come to that with me."

The pattern of family caregiving passed from generation to generation was a reason many of the women referenced when discussing why they continued to care for their parents. In addition, caregivers described their sense obligation to their parent as the reason they continued to care after their parent no longer seemed to be the same person. As one daughter described:

> It's really hard even to call her my mother. I mean it's the body of my mother, but she is not my mother... She is not the woman I grew up with, but legally

> she's my mother. Biologically she is my mother and I will take care of her for as long as she needs care.

4.5.2.1.5 Sense of satisfaction

In this study, sense of satisfaction was defined as a caregiver's satisfaction with efforts to help their parent, the caregiver's sense of achievement, or feelings of fulfillment and contentment from caring. As presented earlier, women who described positive pre-caregiving relationship with their parents often described a sense of satisfaction in caregiving related to this relationship. According to the model of compassion fatigue, a lack of satisfaction is a contributing factor to compassion fatigue, but few caregivers in this study lacked satisfaction in caring for their parent. Many caregivers were content with knowing their parent was well-cared for and that they were the ones able to provide the care to their parent. When asked what she found to be most rewarding, one daughter explained:

> Sometimes she can express that she likes getting her hands washed or getting lotion put on her arms and legs. That's pretty rewarding [to me]—just the fact that I am able to do it. She took care of us for years after we didn't need her to take care of us anymore, and I really feel good that I am able to do that. I really feel fortunate actually that she is here and that I am the one that's closer to her now. Not closer emotionally… but just that I get to see her. I feel like it's a blessing to me that I am the one that gets to spend this time with her. That's a good feeling.

Other daughters shared these same feelings and said that they knew they could be doing something else with their time and acknowledged they might have been missing out on things in life, but stated they would not trade caring for their parent for those other things. Many viewed their time with their parent as a gift or a blessing. One daughter said, "It's not a chore I want to do, but I feel that it needs to be done and I'm glad that I am in a position to do it because I know that they are better off." And another daughter shared, "I was talking with my manager about this and he said, 'you know, it's really a privilege to be able to take care of your parents when they get older' and that's kind of how I feel about it."

Some daughters were surprised when asked the question about finding satisfaction in caring for their parent. These caregivers said they had never been asked this question before and said they had never really thought about it. Caregivers who had not thought about finding satisfaction before shared that they felt they were obligated to care for their parent. As one daughter described:

> That is interesting because I have never stopped to think about it… I guess I would say that I am not dissatisfied but I have never stopped to think about it in terms of if I am satisfied doing this. Again, I think it just goes back to I feel this is the right thing to do, so I don't internalize it and I don't dwell it down to the personal. I don't feel like putting my feelings on hold even though I have never thought about it. I have never thought about it in those terms.

Three caregivers in this study said they were not able to feel satisfaction and described thinking this was due to the progressive nature of dementia. One caregiver stated, "There is no joy. This is a diminishing brain, and a diminishing body. This is depressing. So, she's comfortable and everything. But there's no joy in that caretaking." Another caregiver felt the same, saying, "Not a whole lot. Not a whole lot anymore. Occasionally. But not a whole lot anymore. Cause she just doesn't understand anymore. She just doesn't comprehend anymore."

4.5.2.1.6 Other life demands

Caregivers described other demands on their time, such as illness, changes in lifestyle, social status, and professional or personal responsibilities. Many of the demands caregivers described were from other family members, such as spouses or children. The daughters who were working described feeling that their jobs were demanding. Other women in the study spent time volunteering or doing advocacy work, and many of the women spoke of obligations from church. As one daughter said in summarizing the demands on her time and the chaos she sometimes felt:

> Besides work and stuff, I have some other kind of volunteer work and projects that I'm really interested in doing in my personal life. We just moved this past fall and I still have stuff in getting my house put together. Sometimes I feel like my life is just really chaotic and I have no control… like when these incidents happen, like my mom breaking her hip or some other area in my life kind of

> blows up. Something else is going on, it makes it stressful because I'm kind of spread thin. So when things go well, I feel like I'm handling it all pretty well, all aspects of my life, but then when something goes out of whack in one, then I feel like the other things have to suffer for a while and get neglected.

Many of the women, however, described their family as a source of support and not as a burden and daughters often indicated family, friends, or support groups, when talking about the reasons they continued to be able to care for their parent. As one daughter said,

> And I have a very, very good and understanding husband who is a great support. My children … see her maybe once or twice a year because we visit back and forth… And they ask about her and they are concerned about what is going on and that's nice to be able to talk to them about it. And I can talk to my cousin.

4.5.2.1.7 Traumatic memories

The daughters who mentioned traumatic events described unique experiences, sometimes about their previous relationship with their parent or other times regarding events that occurred during the caregiving experience. Those caregivers who spoke of trauma and their relationship with their parent described feeling fearful that the negativity or abuse in the previous relationship would reoccur. As one daughter describes:

> No, he's not being ugly to me and I haven't experienced yet him yelling at me. I have seen him fly off the handle at somebody else, like somebody in the facility, but he hasn't done it to me yet… and it will be hard if he starts yelling at me and going back to that mode. That's gonna be hard because it's gonna be hard not to take it personally. Since that was a pattern from before, that he would just be really gruff and that will be a problem for me.

Events were also described as creating traumatic memories. One daughter described working in a hospital, hearing a "code stroke" called, and finding out that her mother was the patient and she now felt a sense of dread and fear every time a "code stroke" was called at work now. Another daughter who had an experience in which her mother wandered described a time when her children were young and walked off and she felt the same sense of fear. These daughters, while having different experiences, all

voiced instances of traumatic events that evoked emotional reactions in them when caring for their parent.

4.5.2.1.8 Steep learning curve

Daughters often described that they became a caregiver for a parent following an emergency situation, such as a broken hip, or the death of their other parent who had been the primary caregiver. Even though dementia is a progressive disease, the daughters described feeling as though they had a steep learning curve associated with becoming a caregiver, regardless of the precipitating event for caring. Caregivers said they wished they had "a manual" to let them know what to do. When asked where she learned what to do, one daughter said "from the school of hard knocks" and continued:

> Yeah, I'm afraid there's not a book, because everybody's situation is so different. It's just the same with my son. I have a group of friends, five, who have children with special needs. Every one of our situations, although there are some similarities, they are very different, because [each] person's different, the condition is different, whatever. We kind of joke about, especially with parents, how there's not a book… So it's like being a parent. You learn as you go along and you make mistakes, and sometimes you make a good decision, hopefully most of the time, you know do no harm kind of thing.

Daughters described feeling tasked with not only learning about dementia and how to deal with the symptoms associated with the disease, but also with learning how to navigate an unfamiliar system. Caregivers described needing to take over their parents' finances, dealing with insurance and Veteran benefits, and the difficulty they experienced arranging care for their parent. Daughters caring for a parent at home felt that hiring aides to come in and assist with care was like managing a nursing home, whereas daughters with a parent in long-term care described feeling that the task of finding a long-term care facility for their parent, and then the initial adjustment period after their parent moved, was a full-time job.

4.5.2.2 Outcomes of compassion fatigue

Outcomes of compassion fatigue in formal caregivers include depression, absenteeism, job dissatisfaction and errors (Abendroth & Flannery, 2006; McHolm, 2006; Wenzel, Shaha, Klimmek, & Krumm, 2011) and were explored with daughter caregivers in this study as depression, burden, caregiver strain, and a change in relationship quality. Depression was defined as a depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentrations – in life, not specific to caregiving. Daughters in this study did not say they felt depressed, but described feeling sad about their parent's situation. Correspondingly, the caregivers talked about grieving. As one daughter said, "So I feel grieving. It's constant grieving. It's just grieving the person she was, grieving who I'm pretty sure who she will become, or what she'll become. Frustrated that I can't change it." Caregivers experienced a sense of sadness for the loss of relationship with their parent and anticipated the loss of their parent, but also were grieving for the loss while their parent was still alive. One daughter described the emotions she felt cleaning out her parents' home even while they were still alive and the sadness she felt going through things that obviously meant something to her parents, but that seemingly had no meaning anymore. Another daughter described her sense of loss:

> I could always call her. Just even the other night my daughter and I were fixing something and I said jokingly, "Why don't we call grandma and ask her how this is supposed to be done." because I would always do that. I would be in the middle of cooking something and I would call her, "How do you do this?" "What's the recipe for such and such?" So I have had to realize, and it's hard too because there is not anybody that can be my mom and take care of me (crying), so I have to do that and that's been one of the hardest things I think. Kind of like you're an orphan but somebody's still there.

While not depression, grief and a sense of loss were common themes throughout the interviews and represent some the negative emotions the caregivers discussed about caring for a parent with dementia.

4.5.2.2.1 Burden

Daughters did not describe strong issues with burden, defined for this study as alterations in the caregiver's emotional and physical health, which can occur when care demands outweigh available resources (Given et al., 1992). They used the word burden and spoke of feeling burdened, and one said she felt sad and down, but daughters did not share much detail about burden. One caregiver stated, "Well now it feels like I am the mother and a nurse, and it feels like a burden sometimes." As discussed above with other life demands, daughters often stated they were able to find support or respite care in spite of the seemingly overwhelming life demands. Many of the daughters caring for a parent in their home described utilizing local adult daycare during the day or having aides come in. One caregiver describes this use of other support in relation to demands on her time saying:

> I have to get to class. I have to study… so I put out an APB in my temple and I got another referral for somebody who actually still works with us. She [parent] goes to daycare during the day, but if we have to do something at night or if we want to go away overnight, this woman, she's still present in our lives and she is wonderful.

Daughters described that they felt taking advantage of outside support enabled them to feel less burdened and allowed the caregivers to care for their parent for longer periods of time.

4.5.2.2.2 Caregiver strain

Caregivers described feeling what is defined as caregiver strain, defined as difficulty in performing the caregiver role (Archbold et al., 1990), more often than they described feelings of burden. Daughters said they felt there was too much to do and that they could not do it all, whether it was remembering to pay all of the bills or providing all of the physical care for a dependent parent. Caregiver strain was explained by this caregiver when she said:

> I have to remember so many things. Car upkeep. House upkeep. Her prescriptions. Her Medicare. Her Tricare for life. Anything that comes up. Her doctor's appointments. My doctor's appointments. Deductibles. Bills.

> Telephone calls to be returned. I'm well prepared for it by debt of having been independent, but you know. I've let a few balls drop here and there I guess. But no big ones.

Other daughters said they felt strained, wanted a break, and felt they never had enough time away from their parent. Some caregivers used the term "selfish" to describe times when they felt they did something for themselves that might not have put their parent first. Another daughter describes her response to the situation as the following:

> Sometimes I feel like I just want to go up in a corner and throw up. I just want to purge, but it's reality. I just want to curl up in a ball and cry, but I can't… because I need to take care of my mother… And, it's a gift to be able to take care of my mother. It's a gift to be able to help her and guide her. It's not a gift I wanted, and I would gladly return it.

Daughter caregivers, although stretched thin, described managing to find a reason to continue caring, such as a sense of obligation or satisfaction in caregiving, as reasons they were able to continue caring.

4.5.2.2.3 Change in relationship quality

The most prevalent outcome of compassion fatigue described by daughters in this study was a change in relationship quality between the caregiver and her parent. As described above, caregivers often expressed sadness for the loss of their relationship with their parent and spoke of a relationship without the emotional connections or reciprocity it had before. The parent was often unable to participate in the relationship and sometimes caregivers felt the person they were caring for was not the same person. As one daughter said, "I pray for a cure. Just want her back. I want her back, but it's not feasible either… It'd be great to have her back. She was funny." Another daughter talks about the loss of her relationship with her father saying:

> When I first realized that my dad had dementia, it was very difficult for me because he was still my dad but he wasn't the same person… and that kind of hit home really hard and I realized I don't really have my dad any more. This is not my dad, even though he's still here, he's not the same person. So that was kind of hard cause I always felt like no matter what, what was going on in my life or how bad things were, that I always had my dad that I could count on and he

would always be there and love me and support me and then kind of seeing this part of him go away.

Other caregivers, however, described how their relationship with their parent had improved after caregiving began. One daughter who had experienced a negative relationship with her father said, "There was one time probably two years ago where he was sitting in his chair and I was leaving and he looked up at me and said, "I love you" and he really, I felt for the first time in my life, he actually meant it."

Caregivers also described increasing the physical contact between themselves and their parents and using this contact as a way to stay connected to their parents when they could no longer converse with them. One daughter explained how her father loved for her to kiss him on the cheek and she experienced affection with her father that was not there previously. Another daughter said, "So sometimes we just sit there and she doesn't seem to want to talk and she is maybe nodding off and I just sit there and hold her hand."

In summary, caregivers in this study described many of the contributing factors and outcomes for compassion fatigue that were also experienced by formal caregivers. In addition to factors from the established model of compassion fatigue, daughter caregivers also described additional factors, unique to caring for a parent with dementia and different from experiences of formal caregivers, of previous relationship history to the care recipient and a sense of obligation to continue caring for their parent.

4.5.3 How do adult daughter caregivers for parents with dementia vary in characteristics of compassion fatigue and contributing factors and outcomes, and what patterns emerge in this variation?

Daughter caregivers in this study described the contributing factors for, indications of, and outcomes of compassion fatigue at varying levels. As discussed previously, variation in these characteristics was often described because of the

relationship between caregiver and care recipient and the amount of support a caregiver felt she received. Other specific variables, such as caregiver race, whether the parent was a father or mother, length of time caring, or caregiver employment did not create patterns in compassion fatigue experiences.

4.5.3.1 Previous relationship quality

Many of the daughters who described a negative relationship with their parent prior to becoming a caregiver also described that their parent had existential suffering. These caregivers perceived that their parent did not have a good quality of life or that their parent had no meaning to their life. As one daughter said,

> I wish she could die because if my mother knew the shape she is in, she would absolutely detest it. In fact over the last two years she would have these flashes of lucidity from time to time and she would say, "I wish I had a button I could just turn it off. I am so tired of this". And I know she is. She would like for this to be over and I would love for her for it to be over, but she has absolutely no physical problems so we are just going to have to wait until her brain sufficiently dies for her to go.

In contrast, daughters who described a positive relationship with their parent prior to caregiving often described psychological suffering in their parent compared to the daughters who described negative pre-caregiving relationships. Those describing positive relationships spoke more about how their parent was aware about what was going on and felt that their parent was not always treated with respect. One daughter described about how her friends would avoid contact with her mother and described the frustration and anger she felt because of this. This daughter was also acutely aware of how her mother was suffering, as she described:

> Yes, oh I know it's been difficult for her. This vibrant, beautiful, social outgoing person would tell me from time to time that she felt that she was in the bottom of a deep well and that there were no handholds to climb out of it. And I would say, you know, "why are you doing this?" whatever she was doing, "why are you doing this?" "I don't know. I can't help it."

Caregivers also described the relationship between caregiver and care recipient as the reason for continuing to provide care for their parents. The daughters who

described a particularly negative or neutral prior relationship with their parent discussed caregiving as an obligation more often than women who shared a positive pre-caregiving relationship. Caregivers who described negative relationships used words like “who else will do it”, “it’s expected of me”, “I really don’t think about it very much”, and “it is what you do” when discussing why they cared for a parent. Caregivers describing a negative relationship also recounted the difficulty they sometimes felt in being the caregiver for someone with whom they were not close and shared that they did not find satisfaction in caring for their parent. These caregivers expressed feeling validated in their caregiving through knowing their parent was well-cared for, but did not describe feelings of joy in caring for their parent.

In contrast, the daughters who described a positive prior relationship often described caring for their parent because they wanted to “give back”. These caregivers often said they were grateful for their caregiving experience and found the experience to be rewarding. Daughters with positive relationships described finding validation from their relationship with their parent versus the actual tasks associated with caregiving. Not surprisingly, it was these caregivers describing a positive prior relationship that often shared feeling the greatest sense of sadness for the loss of the relationship with their parent and described more negative emotional outcomes from caring than the daughters describing a negative pre-caregiving relationship.

4.5.3.2 Support

Daughter caregivers in this study described finding support from many different outlets. Most daughters spoke of having a spouse or partner who provided their greatest support and even when spouses were not actively involved in providing care for their parents, the caregivers said they could rely on their spouses for emotional support when needed. Caregivers with siblings nearby also described relying on their

siblings to help care for their parent. Other family members who were close also provided a sense of support to the caregiver and many of the caregivers in this study spoke particularly of cousins who were able to help them care for their parent. Daughters who described feeling more supported shared that they were less distressed by their other life demands or challenges than daughters who described feeling less supported, and also described the support they had as a reason they did not feel helpless and hopeless.

Not all family members provided support, however, and when caregivers described negative support, many of those with brother(s) mentioned that their brothers were not involved in caring for their parent and as being absent from the situation. As one daughter said, her brother was a “non-issue” related to her mother’s care, but when there were issues, caregivers often described financial disagreements with their brothers. Caregivers described these issues as an extra level of complexity to the caregiving situation and described feeling resentful towards their family members.

4.5.3.3 Faith

Caregivers in this study described feeling additional support from their faith or from other members of their faith community. Women who spoke of faith described it as a reason they were not hopeless. Caregivers told stories about going to their church or temple for help in finding aides to assist in caring for their parent, and caregivers who discussed faith said they used prayer as a way to deal with difficult situations. In addition, these caregivers described volunteering or being actively involved in their churches or temple, and felt that this outlet provided them needed time away from caring for their parent.

Adult daughters in this study described varying experiences caring for a parent with dementia and patterns emerged from these experiences. The previous relationship

quality between daughter caregivers and their parents was described in the interviews most often out of the contributing factors and outcomes of compassion fatigue, as well as the indications of compassion fatigue. The amount of support described by the caregiver was also important to the caregiving experience. Patterns in the data suggest that these two factors – relationship quality and support – above many other demographic characteristics of the caregivers, are the most important.

4.6 Discussion

This study aimed to explore the concept of compassion fatigue in adult daughter caregivers for parents with dementia and to identify contributing factors and outcomes of compassion fatigue as specified in Figley's model (Figley, 2002a; Figley & Roop, 2006) that was developed for formal caregiving. As expected, daughters caring for a parent with dementia described some of the manifestations of compassion fatigue that are known to occur in formal caregivers. Daughter caregivers also described many of the contributing factors and outcomes of compassion fatigue identified in the literature (Abendroth & Flannery, 2006; Benoit et al., 2007; Hooper et al., 2010; Keidel, 2002; Udipi, Veach, Kao, & LeRoy, 2008). In particular, daughter caregivers described feelings of helplessness and hopelessness as indicators of compassion fatigue. When exploring the contributing factors for compassion fatigue, daughter caregivers described many of the concepts in the model and also spoke of additional caregiving challenges unique to family caregivers, and not in the model of formal caregivers, that I propose might contribute to or moderate compassion fatigue in this population. Caregivers also described experiencing outcomes of compassion fatigue, predominantly a change in relationship quality with their parent and feelings of caregiver strain. The patterns that emerged in caregivers' descriptions of compassion fatigue in this study were most often described as relationship quality or feelings of support. The findings on the

characteristics of compassion fatigue will be discussed first, followed by the contributing factors and finally the outcomes of compassion fatigue.

4.6.1 Characteristics of compassion fatigue

Adult daughter caregivers in this study described several of the characteristics of compassion fatigue. Previous research on compassion fatigue in formal caregivers has often been theoretical and includes much debate on how to define the concept (Coetzee & Klopper, 2010; Figley, 2002a; Najjar et al., 2009; Sabo, 2011). Thus, the work of this study began with a literature review to fully explore how the concept might address family caregivers and to develop a relevant definition of compassion fatigue for this population (Day & Anderson, 2011). At the outset of this study, compassion fatigue was defined in this study as feelings of anger, inefficacy, apathy, and depression. The empirical indicators of compassion fatigue that were that were explored in the interviews were helplessness, hopelessness, apathy, and disengagement. Caregivers in this study described helplessness and hopelessness, and to a lesser extent disengagement, and no caregivers in the study described apathy. Sabo (2011) asserts the hallmark signs of compassion fatigue are sadness and grief, avoidance, disengagement, and decreased intimacy. The findings from this study support these characteristics and supported the refined definition of compassion fatigue that I proposed for family caregivers.

Compassion fatigue was proposed by Figley as a process and my data suggest it might occur along a continuum. It was difficult in this study to separate the characteristics of compassion fatigue from the proposed outcomes of compassion fatigue. Many of the outcomes proposed a priori in this study might actually be characteristics of compassion fatigue. For example, the caregivers in this study described a decreased relationship quality with their parents that corresponds to the

decreased intimacy proposed by Sabo (2011). Likewise, caregivers described grief and a sense of sadness for the loss of the relationship with their parent. These feelings are in line with other studies on dementia caregiver grief (Furlini, 2001; Meuser & Marwit, 2001; Ott et al., 2007; Sanders, Ott, Kelber, & Noonan, 2008) and changes in relationship quality when caring for a family member with dementia (Furlini, 2001; McGraw & Walker, 2004).

Perry and colleagues (2010) describe particularly negative characteristics of compassion fatigue, especially poor self-care, depleted energy, loss, despair, emotional turmoil, and hopelessness, whereas the present study found some caregivers who were not hopeless and did not feel a sense of loss. The caregivers with a more positive view often described having support as the reason they had hope and felt satisfaction in caring. Caregivers in this study also described faith as a reason they found hope and purpose in caring. Findings from this study suggest that support, from both family and others, and faith play important roles that might be moderating factors for compassion fatigue. Empirical studies on compassion fatigue in formal caregivers discuss the importance of personal coping strategies or self-protection measures (Abendroth & Flannery, 2006; Bourassa, 2012; Wenzel et al., 2011) as well as the importance of peers or team spirit (Collins & Long, 2003; Wenzel et al., 2011) as protective factors or moderators for compassion fatigue.

Findings from this study, in combination with work on compassion fatigue in formal caregivers and the limited work on family caregivers, suggest a refinement to the definition, which I proposed for this study, and to refine the model of compassion fatigue as it applies to family caregivers. Specifically, compassion fatigue in family caregivers might best be understood to have the characteristics of helplessness, hopelessness, disengagement, grief, decreased relationship quality, caregiver strain, and

guilt. Table 6 presents the differences between the revised definition and the previously proposed definition of compassion fatigue.

Table 6: Comparison Between Previous and Revised Definitions of Compassion Fatigue

Previous definition of compassion fatigue	Revised definition of compassion fatigue
Helplessness	Helplessness
Hopelessness	Hopelessness
Disengagement	Disengagement
Apathy	Grief
	Decreased relationship quality
	Caregiver strain
	Guilt

4.6.2 Contributing factors of compassion fatigue

Adult daughter caregivers for parents with dementia described several of the contributing factors of compassion fatigue as they have been detailed in formal caregivers. In this study, the contributing factors were based on the established model of compassion fatigue (Figley, 2002a) and included an exposure to suffering, an empathic concern and empathic response, an inability to detach for the caregiving situation, dissatisfaction with helping the care recipient, other life demands, and traumatic memories. In Figley's model, compassion fatigue is a process that begins when the caregiver is exposed to a care recipient's suffering. Caregivers in this study described three types of suffering in their parents: physical, psychological, and existential. These caregivers' descriptions of suffering correspond to other empirical and theoretical work on suffering (Monin & Schulz, 2009; Monin, Schulz, Martire, et al., 2010; Schulz et al., 2007; Schulz et al., 2010). The perception of suffering by daughter caregivers varied dependent upon the previous relationship quality between caregiver and care recipient. Those caregivers with positive relationships often described only physical suffering while caregivers with negative pre-caregiving relationships described more existential suffering. This is an important distinction and suggests that the pre-

caregiving relationship quality might be a moderator for perception of suffering and possibly compassion fatigue because this is the first step along the process to a caregiver developing compassion fatigue.

Figley proposes that the caregiver must have concern for the person suffering for a caregiver to move along in the process of compassion fatigue, and this exposure to suffering causes an empathic response (Figley, 2002a). Daughter caregivers in this study described an empathic response of protection for their parents. Caregivers felt their response was often effective and described setting their parent up for success. Therefore, even while family caregivers had a prolonged exposure to suffering, their efforts to respond were generally successful. The protection response was limited to physical and psychological suffering, however, and most of the daughters were unable to address their parents' existential suffering and unable to provide a meaning for their parents' lives.

Figley proposes that when an empathic response is coupled with an inability to detach from the caregiving situation and dissatisfaction with helping the care recipient, compassion stress results. In this study, two aspects differed from Figley model because of the nature of family caregiving. Specifically, the daughters describe the quality of the pre-caregiving relationship and their sense of obligation to the parent as important factors in caregiving and these shaped their response to the parent. The daughters described the sense of obligation to the parent as the reason why they were unable to detach completely from caring for the parent. Whereas formal caregivers provide care from a professional obligation and are able to leave their jobs if they desire, family caregivers in this study described strong feelings of responsibility to their parent. One study found that 44% of informal caregivers, with a sample including 61% children caring for a parent, perceived they did not have a choice in becoming a caregiver (R.

Schulz et al., 2012). The caregiver's perception of no choice was a significant predictor for higher levels of emotional stress and physical strain, negative impact of caregiving on physical health. Obligation was described as a reason they continued to care for their parent even when the situation was difficult or when the pre-caregiving relationship had been abusive or negative. Feelings of obligation are unique to family caregivers and are a contributing factor for compassion fatigue that is not addressed in the established model of the process.

Findings related to obligation in this study are similar to previous work on obligation and family caregiving that found daughters provided care to a parent in the context of past abuse out of obligation (Wuest, Malcolm, & Merritt-Gray, 2010). Wuest and colleagues (2010) concluded that caregiving provided validation and reconciliation for the 16 daughters in their sample with abusive parents. Findings from the present study support these conclusions as daughters who described negative pre-caregiving relationships often described caring for their parent due to obligation whereas the daughters who described positive pre-caregiving relationships often described caring because of the positive relationship quality. Similar to the study by Wuest and colleagues (2010), participants in the present study who described negative pre-caregiving relationships often described feeling validated from caring for their parent as opposed to the daughters that found satisfaction in caregiving who described positive relationships. Results from this study suggest that those caregivers who described a negative relationship with their parent would likely be more at risk for compassion fatigue given their inability to detach because of their feelings of obligation and also because these caregivers did not describe a sense of satisfaction and instead found validation from caring for their parent. Therefore, the pre-relationship quality between

caregiver and care recipient might moderate how the caregiver continues along the process from compassion stress to compassion fatigue.

According to Figley, caregivers with compassion stress then proceed to develop compassion fatigue when faced with continued exposure to suffering, other life demands, and traumatic memories. Findings from this study described other life demands caregivers for a parent with dementia experience, such as work and/or school, other family members such as spouses or children, and often volunteer commitments or church involvement. Not surprisingly, these results correspond to other studies on family caregivers that have found daughter caregivers have more family burdens than spousal caregivers and are more likely employed (Conde-Sala et al., 2010; Pinquart & Sorensen, 2011). It is important to note, however, that while these other demands required time from the caregivers, the caregivers often described feeling supported by family or through their faith. Family was described by caregivers as providing small respites and often emotional breaks from the caregiving experience. Caregiver's feelings of support were likely an important moderator for compassion fatigue because the other life demands became less demanding and support provided an additional way for the caregivers to detach themselves from caring at times. Findings from this study suggest that the model be refined by adding the moderators of caregiver's sense of support and faith to the model.

Daughter caregivers in this study described additional areas of frustration and stress related to dealing with the healthcare system and a steep learning curve associated with being a family caregiver. These challenges add additional factors unique to family caregivers that might contribute to compassion fatigue. Similarly, in a study of grief in caregivers for a family member with dementia, Sanders and colleagues (2008) report caregivers described system issues and frustrations and obstacles while

interacting with the healthcare system. A survey of all family caregivers found that 78% of caregivers (National Alliance for Caregiving & AARP, 2009) felt they needed more information in order to provide care, particularly in keeping the care recipient safe at home, managing their own emotional and physical stress, and easy to do activities with the care recipient. In addition, the survey noted that the demand for information has increased in the last five years (National Alliance for Caregiving & AARP, 2009). These learning needs correspond to the steep learning curve experienced by participants in this study and denote an area where family caregivers differ from formal care providers.

Findings from this study provide some detail about the role of traumatic memories in the daughters' caregiving and thus might be a factor in development of compassion fatigue. Perry and colleagues (2010), however, report that traumatic memories were not present in their data from family caregivers caring for a family member in long-term care. Traumatic memories appear important in the compassion fatigue process for formal care providers (Benoit et al., 2007; Boscarino et al., 2004), but one study found that workers with a history of trauma did not experience compassion fatigue and these workers were instead able to use their experiences as a protective factor (Bourassa, 2012). The role of traumatic memories on family caregiver compassion fatigue remains unclear and warrants more research for clarification.

In summary, daughter caregivers described many of the contributing factors that Figley proposed in his model of compassion fatigue. Findings of this study diverge from Figley's model on factors unique to daughter caregivers, including pre-caregiving relationship quality, a sense of obligation to care, the challenges of the healthcare system, and steep learning curve. Differences between daughter caregivers and formal caregivers suggest the need for a revised model of compassion fatigue. A revised model

of compassion fatigue should address these differences, some of which appear to be moderators to the development of compassion fatigue.

4.6.3 Outcomes of compassion fatigue

Outcomes of compassion fatigue in formal caregivers include depression, absenteeism, job dissatisfaction and errors (Abendroth & Flannery, 2006; McHolm, 2006; Wenzel et al., 2011) and were explored with family caregivers in this study as depression, burden, caregiver strain, and a change in relationship quality. As discussed previously, findings from this study suggest that compassion fatigue occurs along a continuum with the outcomes and characteristics of compassion fatigue in combination. Caregivers in this study described changes in their relationship with their parent as well as feelings of caregiver strain. Few caregivers spoke of depression and burden, however, and these findings imply burden and depression might not be as important factors in the process of compassion fatigue as caregiver strain or the relationship between caregiver and care recipient.

Findings similar to the findings from this study regarding caregiver strain have been previously reported in other studies with caregivers for family members of dementia (Judge, Yarry, Looman, & Bass, 2013; Prince et al., 2012; Wolff et al., 2009). Daughters in this study described feeling overwhelmed and shared how they often felt they would like a break. Caregivers' feelings of caregiver strain were contrasted by the feelings of guilt daughters experienced when they were able to take breaks from caregiving. In a study aimed at understating grief in dementia caregivers also found that caregivers described feelings of regret and guilt, particularly related to decisions about care for the care recipient and when placing the care recipient in long-term care (Sanders et al., 2008). Sanders and colleagues (2008) reported that caregivers described negative emotional consequences when they were unable to meet the caregiving needs,

not unlike the caregivers in the present study. When family caregivers feel overwhelmed by the caregiving role, they might also be experiencing compassion fatigue and the complex emotions that arise in caring for a parent with dementia are compounded by the presence of compassion fatigue.

Caregivers in this study did not describe symptoms of depression representative of the prevalence of depression in other dementia caregivers. This result is surprising because other studies with dementia caregivers often find high percentages of participants with depressive symptoms; from 40% to 44% of caregivers (Fisher et al., 2011; Schulz et al., 2008) and very few participants in this study shared that they felt depressed. This study did not include measures of depressive symptoms and it is possible that while the women did not say they were depressed, they would indicate depressive symptoms on a measure. Depression as an established outcome of compassion fatigue in formal care providers and being able to accurately capture this consequence will be important as research on compassion fatigue in family caregivers moves forward.

Findings from this study suggest that it is difficult to distinguish the characteristics of compassion fatigue from the outcomes of compassion fatigue, namely the change in pre-caregiving relationship quality between caregiver and care recipient. This study explored the outcome of changing relationship quality and other proposed outcomes of compassion fatigue in family caregivers and found support for caregiver strain and to a lesser extent burden. Caregivers in this study did not describe depression and findings suggest that caregivers also experience feelings of guilt, often related to caregiver strain. Compassion fatigue is a complex process with many contributing factors and indicators. Little research has been done on compassion fatigue in family caregivers and therefore the outcomes suggested in this study were proposed

based upon work in formal caregivers. Daughter caregivers, however, have a different caregiving experience, one that is particularly based upon the parent-child relationship, and therefore daughter caregivers appear to have different outcomes of compassion fatigue than formal caregivers. These findings suggest an addition to the established model of compassion fatigue to include caregiver strain and guilt.

4.6.4 Limitations

This study had limitations that should be considered when interpreting the study results. All caregivers in this study reported having some type of support, whereas in prior studies, only 68% of caregivers for adult care recipients, including all illnesses, not just dementia, reported having help from at least one unpaid caregiver (National Alliance for Caregiving & AARP, 2009) and 65% of dementia caregivers used at least one community service (Brodaty, Thomson, Thompson, & Fine, 2005). Daughters in this study who provided care in their home used outside services such as adult daycare or had aides come into the home to assist with care. Those that did not, relied on family members for respite care; no one in the study described feeling totally alone caring for their parent. The daughters who cared for a parent in long-term care also reported feeling supported, often from other family members. This might be due to the sampling strategy utilizing support groups and the local Alzheimer's Association chapter. By virtue of this, participants were already seeking help of some kind. It should be noted, however, that five of the women were recruited either by snowball sampling or word of mouth from minority provides, and these women also described having support. It is possible, given the importance of support as a moderator for compassion fatigue, that a sample of women who did not have support would display indications of compassion fatigue to a greater degree than the participants in this study.

Daughters in this study varied in the amount of contact they had with their parent and the amount of contact with a parent might be an important variable for the development of compassion fatigue. Daughters who had a parent in long-term care reported having less contact with their parent, particularly those daughters who visited their parent only one time per week. In comparison, daughters who co-resided with their parent described extended contact and were possibly at greater risk for compassion fatigue due to the extended exposure and amount of care provided. The amount of time providing care is likely an important variable that should be considered and almost half of the daughters in this study reported spending between 2 to 20 hours per week caring for their parent. It is possible a more homogeneous sample of caregivers with an extended contact with the care recipient would likely describe feelings of compassion fatigue to a greater degree than the daughters in this study.

In this study sample, 78% of care recipients were mothers which is somewhat higher than statistics reported for the population which show that among older adults with dementia, roughly two-thirds are women (Alzheimer's Association, 2013). This might be due, in part, to the fact that older men with dementia are more likely to have a living spouse to care for them (Pinquart & Sorensen, 2011; Poysti et al., 2012), whereas older women with dementia have outlived their spouses and therefore the children become the caregivers.

Only cross-sectional data were included in this study as caregivers were interviewed at only one time point because compassion fatigue was proposed to be short lived in formal caregivers (Figley, 2002a). Because it is a process and might potentially wax and wane in intensity, a longitudinal study might have uncovered a greater degree of compassion fatigue in adult daughter caregivers and should be considered in future research. As a cross-sectional study, however, this study provided rich, descriptive data

for many of the concepts in the model and the questions asked allowed women to consider and share past experiences. Women were able to reflect on their feelings and it is likely they would have voiced indications of previous experiences with compassion fatigue.

4.6.5 Implications for Research

Future studies on compassion fatigue in family caregivers should address the limitations of this study. The results from the study endorse the importance of support to family caregivers; however, the pervasiveness of support described by daughters in this study might have limited the prevalence of compassion fatigue in this sample. Future studies on compassion fatigue need to specifically include participants who do not report support from both informal and formal systems. Caregivers without support would likely be at greater risk for compassion fatigue and research with this population would provide even greater detail about compassion fatigue in family caregivers.

Unexpectedly, caregivers in this study did not describe depression and its absence suggests future research. Other qualitative studies on caregivers for family members with dementia have described caregivers sharing mental health problems and even suicidal ideation (O'Dwyer, Moyle, & van Wyk, 2013), so additional research might uncover a greater number of caregivers reporting depression. All caregivers who reported depression to O'Dwyer and colleagues (2013), however, had been diagnosed with depression prior to caregiving and it was not a result of caregiving and therefore not an outcome of compassion fatigue. Of note, caregivers with prior mental health problems described an exacerbation of these problems and caregivers described feeling helpless due to the stress related to caregiving (O'Dwyer et al., 2013)and future research might explore this in more detail. Caregivers with pre-existing depression might be at

even greater risk for compassion fatigue and future research could explore this possibility.

Additional opportunities for research arise from the results in respect to daughters' feelings of obligation. Findings from this study suggest that obligation was a reason daughters continued to care for a parent even when the parent had been abusive or when the caregiving situation was quite difficult. An inability to detach is an important contributing factor to compassion fatigue, as is empathy, and it is interesting that those caregivers who described caring due to a sense of obligation and not because of a close relationship with their parent also described empathy and perceived suffering in their parent. In a review of theories of filial obligation, Stuifbergen and Delden conclude that children have the "duty to care about our parents" (Stuifbergen & Delden, 2011, p. 70) and that care for elderly parents is not an adult child's duty. These findings suggest an association between obligation and empathy and further research might explore this relationship.

Future research should also include longitudinal data to better describe the development process of compassion fatigue and assess its dynamics. Most research on compassion fatigue in formal caregivers has been cross-sectional (Abendroth & Flannery, 2006; Adams et al., 2006; Benoit et al., 2007; Maiden et al., 2011) which limits the understanding of compassion fatigue as a process occurring over time. Only a small number of longitudinal studies have been done with formal caregivers (Bourassa, 2012), but the longitudinal studies have been able to explore and demonstrate protective factors for compassion fatigue (Bourassa, 2012). Little remains known, however, about the trajectory of compassion fatigue and longitudinal studies with family caregivers might provide additional information about compassion fatigue as it changes over time.

A final important implication for future research is revising the model of compassion fatigue to more accurately capture the experience of family caregivers. Daughter caregivers described many of the characteristics and contributing factors for compassion fatigue, but also described factors unique to family caregivers and different from formal caregivers. These factors were the pre-caregiving relationship quality, a sense of obligation to care, the challenges of the healthcare system, and steep learning curve and they appear to moderate compassion fatigue in daughter caregivers. Therefore, a revised model needs to include these factors and address the differences between family caregivers and formal caregivers.

4.6.6 Implications for Practice

The results from this study suggest several important implications for practice. Foremost, the significance of support as a potential moderating factor for development of compassion fatigue cannot be overlooked. Practitioners, therefore, should assess caregivers' use of support and strongly encourage caregivers to use support, paid or unpaid. If caregivers are not using support, health care providers should explore their reasons and find ways to help them overcome these barriers. Caregivers in this study stressed the importance of adult daycare and in-home aides and described how these options allowed them to continue caring for their parent at home. A few caregivers, however, were unaware of these resources and practitioners need to work as an interdisciplinary team to address all possible ways in which the caregiver might be supported in order to continue providing care at home, and to protect against the development of compassion fatigue.

Similarly, this study underlined the steep learning curve faced by caregivers for a family member with dementia. This steep learning curve was closely associated with the caregivers feeling that the healthcare system was ill prepared or incapable of caring

for their parent, in addition to the caregiver themselves feeling ill prepared to care for their parent. Therefore, changes need to be made to simplify how the caregivers interact with the healthcare system and caregivers need to be made to feel a greater sense of control in the situation. Participants in this study were all provided a two-page handout (Appendix C) where one page listed all of the support groups in the local area and the other page was a list of resources, including both local and online resources, where caregivers could find information. While this handout did not provide all of the information a caregiver might need, the handout provided enough information to direct caregivers where to go to find what they might need. Providing caregivers with a more detailed handout or a book of information might overwhelm them, but a brief handout helps caregivers figure out where to go next and offers them a sense of control in a situation where caregivers often described feeling helpless. The handouts were well-received by caregivers in the study and even though many of the participants were recruited through support groups, they had not been provided a list of resources such as the handout.

Another important implication for practice from this study is the prevalence of perceived suffering and the caregivers' desire to protect their parents. Health care providers, and nurses in particular, are in an opportune position to address care recipient suffering and it is important to note that most of the suffering described by the caregivers related to psychological or existential suffering with very little was perceived physical suffering. Therefore, assisting caregivers to find meaning in the life of the care recipient might reduce the caregiver's perception of existential suffering. Similarly, allowing the caregiver to focus on meaning in the life of the care recipient helps foster the relationship between the caregiver and care recipient. The caregiver might be able to find additional sources of satisfaction when the relationship between caregiver and care

recipient is brought to the forefront. Most caregivers in this study who expressed having a positive relationship with their parent prior to caregiving were able to find satisfaction and validation in caring for their parent and this was an important to the development of compassion fatigue.

4.7 Conclusion

This study contributes an understanding of compassion fatigue in adult daughter caregivers that differs in some ways from formal caregivers. It was the first study with the specific aim of exploring the concept in family caregivers and thus provides a detailed description of the concept in daughter caregivers for a parent with dementia. Findings from this study suggest new areas for research and practice and propose the need for a revised model of compassion fatigue in family caregivers. The findings related to the importance of previous relationship quality to the caregiving experience are another major contribution to the caregiving and compassion fatigue literature from this study. Previous relationship quality between caregiver and care recipient affected many aspects of caregiving in this study, including the caregiver's perception of care recipient suffering, the feelings of satisfaction or sense of validation from caring, and also provided the motivating factor for continuing to care for their parent. This study provides new knowledge about the experience of family caregivers and is the starting point for new ways to address caregiving challenges related to compassion fatigue.

5. Discussion

> Sometimes I feel like I just want to go up in a corner and throw up. I just want to purge, but it's reality. I just want to curl up in a ball and cry, but I can't… because I need to take care of my mother… And, it's a gift to be able to take care of my mother. It's a gift to be able to help her and guide her. It's not a gift I wanted, and I would gladly return it.

This quote, from a daughter caring for her mother with dementia, illustrates the negative emotional responses caregivers for family members with dementia often experience and the challenges they face. Family caregivers, like the daughter quoted from this dissertation study, might also be at risk for compassion fatigue. Compassion fatigue is a concept that was introduced to the health care community as feelings of anger, inefficacy, apathy, and depression resulting from a caregiver's inability to cope with devastating stress (Joinson, 1992). Compassion fatigue was first observed in nurses and later in other caring professionals such as social workers and psychologists (Figley, 2002a; McHolm, 2006; Sabo, 2006) and the definition was adapted to focus on prolonged exposure to suffering as one of the primary causes (Figley, 1995). In the professional caregiver literature, compassion fatigue was described theoretically to have an acute onset (Figley, 2002a; Sabo, 2006) and engendered negative emotional responses to caregiving such as helplessness, hopelessness, an inability to be empathic, and a sense of isolation (Adams et al., 2008; Joinson, 1992; McHolm, 2006; Robins et al., 2009).

Although compassion fatigue has not been studied in family caregivers providing care at home, their experiences, particularly those of adult daughter caregivers for parents with dementia, appear to create a foundation for developing compassion fatigue. For this reason, it was important to investigate compassion fatigue in this growing population of caregivers. This dissertation explored compassion fatigue in daughter caregivers for parents with dementia. The dissertation aims were to 1) identify common themes across the literature on compassion fatigue and to apply these

themes and the existing model of compassion fatigue to informal caregivers for family members with dementia, 2) analyze secondary data from Project ASSIST to substantiate a need for further study of compassion fatigue in adult daughter caregivers of a parent with dementia, 3) explore the feasibility of studying compassion fatigue in family caregivers, and 4) explore compassion fatigue and the contributing factors and potential outcomes of compassion fatigue in adult daughter caregivers for parents with dementia.

To accomplish these aims, the model of compassion fatigue (Figure 5) developed by Figley (2002a) was used as a guide. The model has been used as the theoretical basis in other studies examining compassion fatigue in formal caregivers (Abendroth & Flannery, 2006; Adams et al., 2006; Benoit et al., 2007; Figley, 2002a), one small study (N=5) with family caregivers (Perry et al., 2010), and a secondary analysis of nurse-daughter caregivers (Ward-Griffin et al., 2011), but this was the first research to fully explicate the model in family caregivers for parents with dementia.

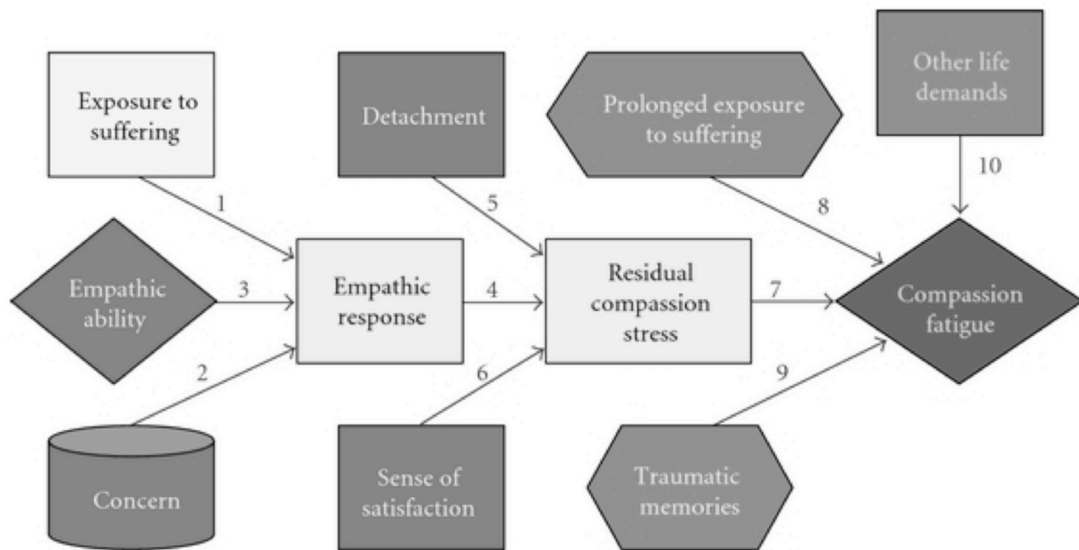


Figure 5: The Compassion Fatigue Process (Figley & Roop, 2006)

The dissertation consisted of three studies. The first study, a review of the literature addressed aim 1 of the dissertation as I applied the established model of compassion fatigue to family caregivers. The literature review found evidence to support the components of the established model of compassion fatigue and findings suggested additional work was needed on the concept of compassion fatigue in family caregivers. The second study, a secondary analysis pilot study addressed aim 2 and aim 3 of the dissertation study. Findings from this study provided support for more in-depth exploration of the concept of compassion fatigue in family caregivers. The third study of the dissertation was a qualitative study exploring the concept of compassion fatigue in daughter caregivers for parents with dementia. This larger study addressed aim 4 and findings from the study provided support for many of the factors related to compassion fatigue but also suggested revisions to the established model of compassion fatigue were needed. In this chapter, I will discuss the important findings from each study. Following the findings, I will offer a revised model of compassion fatigue in family caregivers and suggest ways in which certain changes to the model might also be applicable to formal caregivers. To conclude, I will discuss the implications of this dissertation for research and practice.

5.1 Study 1: Review of the literature

The first study of this dissertation was an application of the concept of compassion fatigue to family caregivers (Day & Anderson, 2011) by reviewing the literature. This literature review addressed aim 1 of the dissertation: to identify common themes across the literature on compassion fatigue and to apply these themes and the existing model of compassion fatigue to informal caregivers for family members with dementia. In this review, the established model of compassion fatigue was used as a framework to help theoretically understand the elements of the model as they might be

expressed in family caregivers. Possible limitations of the model were identified in the literature review; these limitations where noted by an absence of literature to support the model element of traumatic memories in family caregivers and the influence these memories might have on the caregiver's experience. In addition, little research was found in the literature about the importance of the emotional relationship between family caregiver and care recipient and how this might affect the caregiver's development of compassion fatigue. Findings from the literature review suggested further empirical research on the concept in family caregivers in order to fully understand compassion fatigue, and the contributing factors for and outcomes of compassion fatigue, in family caregivers.

5.2 Study 2: Project ASSIST Secondary Analysis Pilot Study

After the concept of compassion fatigue was considered theoretically in family caregivers, the next step in this dissertation was to begin empirical work exploring compassion fatigue in family caregivers. To accomplish this, I conducted a pilot study addressing dissertation aim 2) to substantiate a need for further study of compassion fatigue in adult daughter caregivers of a parent with dementia, and aim 3) to explore the feasibility of studying compassion fatigue in family caregivers. This pilot study was the first to explore the concept of compassion fatigue among daughters caring for parents with dementia at home and the study was a secondary analysis of interviews with six adult daughter caregivers all caring for mothers from Project ASSIST for Chronic Illness Caregivers (Assistance, Support, and Self-health Initiated through Skill Training. Qualitative analysis for this study identified four themes: (a) uncertainty, (b) doubt, (c) attachment, and (d) strain.

The uncertainty theme was related to the adult daughter caregivers feeling unsure when caring for their mothers. Often, their uncertainty was related to dementia

and the trajectory of illness. Adult daughter caregivers often stated they were uncertain how to respond in a situation and were fearful that something distressing would happen to their mothers if they did not act appropriately. Other times, caregiving daughters expressed doubt about their ability to meet their parent's needs, feeling a discrepancy between their expectations for themselves as caregivers and the way in which they were actually caring for their mothers. Findings from the pilot study also found daughters caring for mothers with dementia were emotionally attached to their mothers and expressed willingness to care for them. These caregivers also described satisfaction from caregiving. All of the daughter caregivers in the pilot study described competing life demands. Caregivers' competing demands ranged from husbands and jobs, to church activities and grandchildren. Daughter caregivers had to take time from other activities to care for their mothers and often felt that they were missing out on things.

These four themes were notably connected to the contributing factors for compassion fatigue, particularly empathic ability and empathic concern, inability to detach, and other life demands. Findings from this pilot study were significant because they suggested for the first time that family members caring for an older adult at home might be at risk for developing compassion fatigue. In addition, findings from this pilot provided further justification, along with the literature review, for further research on compassion fatigue in this population and detailed the important issues related to family caregiving of attachment, uncertainty, and doubt.

5.3 Study 3: Compassion fatigue in adult daughter caregivers for parents with dementia

Drawing on the results from the pilot study and the literature review, a larger study was conducted to address aim 4 of the dissertation: to explore compassion fatigue and the contributing factors and potential outcomes of compassion fatigue in adult

daughter caregivers for parents with dementia. This study was qualitative analysis of in-depth interviews with adult daughters caring for a parent with dementia and answered three research questions:

- What are the characteristics of compassion fatigue described by adult daughter caregivers for parents with dementia?
- What do adult daughter caregivers for parents with dementia describe as contributing factors and outcomes of compassion fatigue?
- How do adult daughter caregivers for parents with dementia vary in characteristics of compassion fatigue and contributing factors and outcomes, and what patterns emerge in this variation?

The study sample consisted of 18 adult daughter caregivers (17 daughters, 1 daughter-in-law) who provided an average of 60.25 hours/week of care to their parent. Caregivers either lived with their parent (8 caregivers) or visited at least once a week (10 caregivers) and provided care to their parent to help them take care of themselves. Daughter caregivers ranged in age from 36 years old to 66 years old and had an average age of 55.9 years. The sample consisted of 13 White, non-Hispanic, 1 White, Hispanic, 3 Black, and 1 mixed race American Indian/Black caregivers.

5.3.1 Characteristics and outcomes of compassion fatigue

Adult daughter caregivers in the study described certain characteristics of compassion fatigue previously identified in formal caregivers. In particular, daughters experienced helplessness and hopelessness, and to a lesser degree, disengagement. There were caregivers who denied feelings of compassion fatigue and these caregivers often described support from other family members or faith as the reason they were able to feel capable or had hope. Apathy, defined as a lack of interest or concern regarding

caregiving, is a characteristic of compassion fatigue that was present in formal caregivers, but no caregivers in this study expressed feelings of apathy.

Compassion fatigue was proposed by Figley as a process (2002a) and my data suggest it might occur along a continuum. It was difficult in this study to separate the characteristics of compassion fatigue from the outcomes of compassion fatigue that I proposed at the beginning of the study. Many of the outcomes proposed a priori in this study might actually be characteristics of compassion fatigue. For example, the caregivers in this study described a decreased relationship quality with their parents. Likewise, caregivers described grief and a sense of sadness for the loss of the relationship with their parent. These feelings are in line with other studies on dementia caregiver grief (Furlini, 2001; Meuser & Marwit, 2001; Ott et al., 2007; Sanders et al., 2008) and changes in relationship quality when caring for a family member with dementia (Furlini, 2001; McGraw & Walker, 2004).

Findings from this study, in combination with work on compassion fatigue in formal caregivers and the limited work involving family caregivers, suggest the need to refine the definition and to revise the model of compassion fatigue as it applies to family caregivers. Specifically, compassion fatigue in family caregivers might best be understood to have the characteristics of helplessness, hopelessness, disengagement, grief, decreased relationship quality, caregiver strain, and guilt. Table 7 presents the differences between the revised definition and the previously proposed definition of compassion fatigue.

Table 7: Comparison Between Previous and Revised Definitions of Compassion Fatigue

Previous definition of compassion fatigue	Revised definition of compassion fatigue
Helplessness	Helplessness
Hopelessness	Hopelessness
Disengagement	Disengagement
Apathy	Grief
	Decreased relationship quality
	Caregiver strain
	Guilt

5.3.2 Contributing factors of compassion fatigue

In the larger, qualitative study, adult daughter caregivers for parents with dementia described several of the contributing factors of compassion fatigue as they have been detailed in formal caregivers. In this study, the contributing factors were based on the established model of compassion fatigue (Figley, 2002a) and included an exposure to suffering, an empathic concern and empathic response, detachment, sense of satisfaction, other life demands, and traumatic memories. In Figley's model (Figley, 2002a), compassion fatigue is a process that begins when the caregiver is exposed to a care recipient's suffering. Caregivers in this study described three types of suffering in their parents: physical, psychological, and existential. The perception of suffering by daughter caregivers varied dependent upon the previous relationship quality between caregiver and care recipient. Those caregivers with positive relationships often described only physical suffering while caregivers with negative pre-caregiving relationships described more existential suffering. This is an important distinction and suggests that the pre-caregiving relationship quality might be a moderator for perception of suffering and possibly compassion fatigue given this is the first step along the process to a caregiver developing compassion fatigue.

To move along in the process of compassion fatigue, Figley proposes (2002a) that the caregiver must have concern for the person suffering and this exposure to suffering

causes an empathic response. Daughter caregivers in this study described empathic responses including protection for their parents and setting their parents up for success. When an empathic response is coupled with an inability to detach from the caregiving situation and dissatisfaction with helping the care recipient, compassion stress results. In this study, two aspects differed at this point from Figley's model because of the nature of family caregiving. Specifically, the quality of the pre-caregiving relationship and the daughter's sense of obligation were important factors described that shaped their response to their parent. The daughters described a sense of obligation to their parent as one reason why they were unable to detach completely from caring for the parent. Obligation was described as a reason they continued to care for their parent even when the situation was difficult or when the pre-caregiving relationship had been abusive or negative. Feelings of obligation are unique to family caregivers and are a moderating factor for compassion fatigue that is not addressed in the established model of the process.

According to Figley (2002a), caregivers with compassion stress then proceed to develop compassion fatigue when faced with continued exposure to suffering, other life demands, and traumatic memories. Caregivers from this study described other life demands, such as work and/or school, other family members such as spouses or children, and often volunteer commitments or church involvement. It is important to note, however, that while these other demands required time from the caregivers, the caregivers often described feeling supported by family or through their faith. Caregivers described family as providing small respites and often emotional breaks from the caregiving experience. Caregiver's feelings of support were likely an important moderator for compassion fatigue because the other life demands became less

demanding and support provided an additional way for the caregivers to detach themselves from caring at times.

Daughter caregivers in this study described additional areas of frustration and stress related to dealing with the healthcare system and a steep learning curve associated with being a family caregiver. Daughters described feeling tasked with not only learning about dementia and how to deal with the symptoms associated with the disease, but also with learning how to navigate an unfamiliar system. Formal caregivers have training and education in dealing with these issues (Bourassa, 2012), whereas family caregivers report feeling a lack of choice in becoming a caregiver (Richard Schulz et al., 2012) and family caregivers do not always feel prepared and unpreparedness predicts negative caregiving outcomes (Archbold et al., 1990; Henriksson & Årestedt, 2013; Schumacher et al., 2008). These challenges add additional factors unique to family caregivers that might contribute to compassion fatigue.

Findings from this study provide some detail about the role of traumatic memories in the daughters' caregiving and thus might be a factor in development of compassion fatigue. Traumatic memories appear important in the compassion fatigue process for formal care providers (Benoit et al., 2007; Boscarino et al., 2004), but one study found that workers with a history of trauma did not experience compassion fatigue and these workers were instead able to use their experiences as a protective factor (Bourassa, 2012). The role of traumatic memories on family caregiver compassion fatigue remains unclear and warrants more research for clarification.

Findings of this study diverge from Figley's model on factors unique to daughter caregivers, including pre-caregiving relationship quality, a sense of obligation to care, the challenges of the healthcare system, and steep learning curve. Differences between daughter caregivers and formal caregivers on these factors suggest the need for a

revised model of compassion fatigue. A revised model of compassion fatigue should address these differences, as well as include the role of support as a moderator that does not appear on the established model. The following section will propose a revised model of compassion fatigue for family caregivers, further discuss where the revised model differs from the established model developed by Figley (2002a), and suggest changes to the model as it applies to formal caregivers as well.

5.4 A revised model of compassion fatigue

It is essential to note where daughter caregivers differed from the established model of compassion fatigue and note important experiences unique to family caregivers that might moderate their development of compassion fatigue. Daughter caregiver's experiences caring for a parent with dementia diverged from Figley's model (2002a) on factors unique to family caregivers regarding their pre-caregiving relationship quality, sense of obligation to care, challenges of the healthcare system, and steep learning curve. In addition, daughter caregivers underscored the importance of support as an important moderator for compassion fatigue. Although support has been shown to affect formal caregivers' experiences with compassion fatigue (Abendroth & Flannery, 2006; Benoit et al., 2007; Boscarino et al., 2004; Bourassa, 2012; Collins & Long, 2003; Wenzel et al., 2011), it was not included in the Figley's model. Therefore, as shown in Figure 6 (full-page in Appendix G), this revised model includes the pre-caregiving relationship, sense of obligation, steep learning curve, and support. The revised model also presents the revised definition of compassion fatigue in family caregivers: helplessness, hopelessness, disengagement, grief, and decreased relationship quality, as well as caregiver strain and guilt.

In addition, this revised model of compassion fatigue addresses the existing limitations of Figley's model identified by Sabo (2011) in her theoretical work reflecting

on the concept of compassion fatigue. The limitations she notes include the exclusion in Figley's model of any benefit the caregiver might perceive from the relationship with the care recipient, and also the protective role this might provide for the caregiver (Sabo, 2011). Figley's model of compassion fatigue shows compassion fatigue as a linear process and does show how the caregiver might "get off the run-away train" (Sabo, 2011, p. 3), whereas this revised model includes moderators of compassion fatigue that provide points where caregivers might stop the process and prevent compassion fatigue from developing. Some findings of this study related to proposed moderators might also apply to formal caregivers and future work could consider such modifications to Figley's model as a applied to formal caregivers. In the following section, I note where the revisions might apply to both family caregivers and formal caregivers.

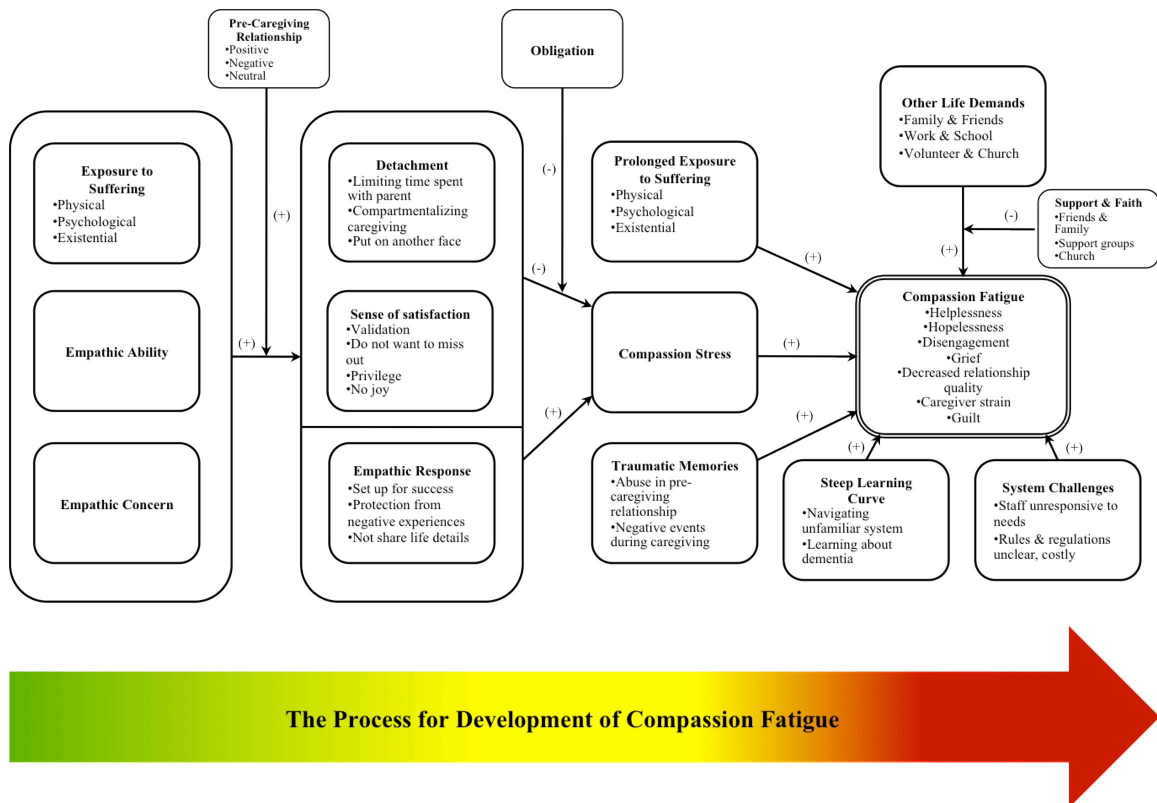


Figure 6: The Revised Compassion Fatigue Process for Family Caregivers

5.4.1 Pre-caregiving relationship quality as a moderator

Previous relationship quality between adult daughter caregiver and parent care recipient was a factor central to the caregiving experience for all of the caregivers in this dissertation. Daughters in both the pilot study and the larger qualitative study described how their pre-caregiving relationship with their parent was affecting their present experience as a caregiver. As shown in the model, the pre-caregiving relationship quality is a moderator between the caregiver's exposure to suffering, empathic ability, and empathic concern and the empathic response, detachment, and sense of satisfaction. Findings of this dissertation suggested the hypothesis that previous relationship quality affects the caregiver's perception of their parent's suffering, their empathic ability, and empathic concern. Daughters perceived different types of suffering and reacted differently to the suffering based upon how they viewed their pre-caregiving relationship with their parent. These differences in turn affected how they proceeded toward the development of compassion fatigue because those caregivers with positive pre-caregiving relationships more often described only physical suffering and the caregivers responded to this suffering with protection toward their parent. These actions of protection were often described as successful and therefore these caregivers would not continue along the process because there would not be suffering to respond empathically. Likewise, the pre-caregiving relationship was also a factor in the way caregiver's found satisfaction in providing care for their parent. Daughters who described positive pre-caregiving relationships described more satisfaction in caring for their parent and given that a lack of satisfaction is the contributing factor, these women would also not be likely to continue along the process of compassion fatigue. The established model of compassion fatigue does not incorporate the pre-caregiving relationship, nor does it acknowledge the benefits the

relationship might have on the caregiving experience. This limitation to the established model was noted by Sabo (2011) this has been addressed by adding the pre-caregiving relationship to the revised model as a moderator.

It is possible that the pre-caregiving relationship, which is unique to family caregivers, has implications for the role that the caregiving relationship might has a moderator for formal caregivers. In a study of compassion fatigue in genetic counselors, Benoit and colleagues (2007) report the counselors were emotionally invested in their patients, yet the established model does not incorporate this closeness. Another study of compassion fatigue in oncology nurses describe the close attachment between nurse and patient that results from the extended time oncology nurses often care for their patients (Wenzel et al., 2011). In this study, some nurses described feelings of loss and grief due to their relationship. The revised model includes the pre-caregiving relationship and even while the nature of relationship between family caregiver and care recipient, and formal caregiver and patient are different, the pre-caregiving relationship or the relationship that develops over the course of caring that creates a shared history between caregiver, formal or family, and care recipient is important.

5.4.2 Obligation as a moderator

Daughter caregivers are notably different from formal caregivers in pre-caregiving relationship due to the sense of obligation a daughter feels to her parent. Therefore, obligation is an important factor closely related to pre-relationship quality that must be added to the model of compassion fatigue. Many daughters described feelings of obligation to care for their parent, though to differing degrees, often coinciding with how they described their pre-caregiving relationship. Daughters who described more feelings of obligation often described less satisfaction and described feeling less able to detach from the caregiving situation. Figley's model proposes that

caregivers who are unable to detach are at greater risk for continuing to develop compassion fatigue and I proposed, based on this dissertation, that the caregiver's sense obligation, moderates detachment and thus would reduces the influence of detachment as a factor in developing compassion fatigue. Therefore, obligation as a moderator has been added to the revised model of compassion fatigue.

5.4.3 Support and faith as moderators

The amount of support received by the caregiver and a caregiver's faith are other important moderators for compassion fatigue that has also been added to the revised model. Caregivers in this study were all able to find sources of support, often from other family members. Even when family members placed demands on the caregiver's time, the caregivers in this study were often able to rely on their family for help when needed. Empirical studies on compassion fatigue in formal caregivers discuss the importance of personal coping strategies or self-protection measures as protective factors against a formal caregiver developing compassion fatigue (Abendroth & Flannery, 2006; Bourassa, 2012; Wenzel et al., 2011). Studies also demonstrate the importance of peers or team spirit (Benoit et al., 2007; Boscarino et al., 2004; Collins & Long, 2003; Wenzel et al., 2011) to formal caregivers as moderators for compassion fatigue. The established model of compassion fatigue, however, does not include these protective factors. Findings from this study, in combination with findings from other studies of compassion fatigue in formal caregivers, suggest adding a caregiver's sense of support and faith to the model as moderators for compassion fatigue to refine the model. This change might apply to both formal and family caregivers. The revised model incorporates support and faith as important moderators to the model for family caregivers.

5.4.4 System challenges as a contributing factor

The established model of compassion fatigue does not account for system challenges the caregiver might face. Daughter caregivers described difficulty dealing with the healthcare system and often felt frustrated and helpless because of these difficulties. In addition, daughters described feeling that the healthcare system was ill prepared or incapable of caring for their parent. Caregivers with family members in long-term care described feeling frustrated with supervision their family member received, and felt as though they had to be their parent's voice because their parent was unable to speak up for himself or herself. Caregivers recounted times when they would talk to the staff at the long-term care facility about what their parent would like, but felt as though the staff would not, or could not, do things to accommodate these preferences. System challenges seemed to increase the caregiver's negative emotions and, when they are unable to overcome these challenges, daughters were at an increased risk for developing compassion fatigue.

The challenges in dealing with a complex healthcare system are not unique to family caregivers, and formal caregivers, particularly nurses, often face system challenges when providing care to patients. Research on compassion fatigue in formal caregivers demonstrates the factor system challenges plays on a care provider developing compassion fatigue (Abendroth & Flannery, 2006; Hooper et al., 2010; Keidel, 2002), yet this factor is missing from the established model of compassion fatigue. The revised model of compassion fatigue includes system challenges as a contributing factor of compassion fatigue and this addition is likely applicable to formal caregivers in addition to family caregivers.

5.4.5 Steep learning curve as a contributing factor

Daughter caregivers described a steep learning curve while caring for a parent with dementia. Daughters in both the pilot study and the larger qualitative study described feelings of doubt and uncertainty and these feelings were often about how to best care for their parent. Family caregivers do not receive the training formal caregivers have; this is a factor where they differ from formal caregivers and an important point to include in the revised model of compassion fatigue. Findings from this dissertation are supported by conclusions from a qualitative study on compassion fatigue in Adult Protective Services social workers (Bourassa, 2012). Bourassa (2012) reports social workers describing the importance of their training and education in enabling them to establish boundaries. Through the boundaries, social workers did not experience compassion fatigue (Bourassa, 2012). Without the benefit of training or education described by the social workers, family caregivers might be at greater risk for developing compassion fatigue and therefore the steep learning curve has been added as a contributing factor in the revised model of compassion fatigue in family caregivers.

In summary, as shown in the revised model of compassion fatigue in family caregivers, the important moderators of pre-caregiving relationship quality, obligation, support, and faith have been added. In addition, daughter caregivers described a frustration with the healthcare system and the steep learning curve they felt in caring for a parent with dementia. These factors have also been added to the revised model of compassion fatigue. Another important difference between the established model of compassion fatigue and the revised model lies within the definition of compassion fatigue itself; the revised characteristics are helplessness, hopelessness, disengagement, grief, decreased relationship quality, caregiver strain, and guilt. Findings from this dissertation also suggest possible outcomes of compassion fatigue are caregiver strain

and guilt, however, these outcomes might in fact be additional characteristics of compassion fatigue. More research is needed to understand these differences. The outcomes of caregiver strain and guilt have been added tentatively to the revised model of compassion fatigue.

5.5 Implications for future research

Findings from this dissertation suggest the need for additional research on compassion fatigue in family caregivers. A future study might include family caregivers who had been providing care at home and evaluate these caregivers at the time, or shortly after, they place a parent in a long-term care facility. Previous caregiving studies have explored family caregivers' reasons for placement (Davies & Nolan, 2004; Ryan & Scullion, 2000), though none have specifically looked at compassion fatigue as a causal factor. Family members describe opting for placement of the care recipient due to an inability to cope and caregivers describe feelings of guilt, helplessness, and sadness that occur after placement (Ryan & Scullion, 2000). This period of time is traumatic for family caregivers (Davies & Nolan, 2004) and this situation might be complicated by the presence of compassion fatigue.

Future research should also include longitudinal data to better describe the development process of compassion fatigue and assess its dynamics. Most research on compassion fatigue in formal caregivers has been cross-sectional (Abendroth & Flannery, 2006; Adams et al., 2006; Benoit et al., 2007; Maiden et al., 2011) which limits the understanding of compassion fatigue as a process occurring over time. Only a small number of longitudinal studies have been done with formal caregivers (Bourassa, 2012), but the longitudinal studies have been able to explore and demonstrate protective factors for compassion fatigue (Bourassa, 2012). Little remains known, however, about

the trajectory of compassion fatigue and longitudinal studies with family caregivers might provide additional information about compassion fatigue as it changes over time.

The findings of this suggest that future work needs to consider the difference between spousal and daughter caregivers. The results from this dissertation are specific to adult daughter caregivers for parents with dementia and there are differences between spousal caregivers and family caregivers that might affect spousal caregivers' risk for compassion fatigue. Spousal caregivers are more likely to share a household with the care recipient (Pinquart & Sorensen, 2011), thus having the opportunity for a prolonged exposure to suffering. In addition, spousal caregivers have worse physical health, provide more hours of care, have less informal support, and higher levels of depression than adult children caregivers (Pinquart & Sorensen, 2011), but spousal caregivers are also more likely to accept caregiving with affection and dignity and are more knowledgeable and realistic (Meuser & Marwit, 2001). Such differences in sociodemographic variables, use of resources, and psychological stressors will likely affect the development of compassion fatigue. Additional research on compassion fatigue with spousal caregivers would likely illuminate any differences in their experience of compassion fatigue compared to adult daughter caregivers. Likewise, sons were not included in this dissertation and their distinctive experiences will likely affect how they develop or are protected from compassion fatigue.

Future research focusing on all types of dementia caregivers will be helpful to clarify differences between daughter caregivers compared to spousal and son caregivers, and can validate the proposed model of compassion fatigue in a broader sample of family caregivers. After compassion fatigue is understood in a wider population of informal caregivers, interventions might be developed to help caregivers "get off the run-away train" (Sabo, 2011, p. 3). Additional research will also provide more empirical

data about the essential concepts to include in a measure of compassion fatigue. Current measures of compassion fatigue are specific to formal caregivers and do not address important considerations for family caregivers like obligation, previous relationship quality, or support.

Findings from this study might be applicable to other populations of caregivers, particularly caregivers in Asian countries such as China and Korea. Caregivers in China are more often women and care for a parent is not recognized by China or supported financially by Chinese society (Zhan & Montgomery, 2003). Chinese women caregivers are likely at risk for compassion fatigue due in part to the changing family structures, decline in coresidence (Zimmer & Kwong, 2003), and the lack of resources available to these caregivers (Zhan & Montgomery, 2003; Zimmer & Kwong, 2003). The longstanding one-child policy in China means that children will have no siblings to provide the support that was important to the women in this study (Zhan, 2005). In addition, caregivers in Asian countries often have a high sense of obligation to care for their parent or filial piety (Han et al., 2008; Zhan & Montgomery, 2003), and this sense of obligation also puts them at increased risk for compassion fatigue. Future research might focus on these caregivers, as the implications for compassion fatigue appear to extend to international caregivers as well.

5.6 Implications for practice

The results from this dissertation suggest several important implications for practice. Foremost, the significance of support as a moderating factor for compassion fatigue cannot be overlooked. Practitioners need to assess caregivers for their use of support and strongly encourage caregivers to find some kind of support, paid or unpaid. If caregivers are not using support, health care providers should explore why and find ways to help caregivers overcome these barriers. Caregivers in this dissertation

stressed the importance of adult daycare and in-home aides and described how these options allowed them to continue caring for their parent at home. A few caregivers, however, were unaware of these resources and practitioners need to work as an interdisciplinary team to address all possible ways in which the caregiver might be supported in order to continue providing care at home, and to protect against the development of compassion fatigue.

Similarly, this dissertation underlined the steep learning curve faced by caregivers for a family member with dementia. This steep learning curve was closely associated with the caregivers feeling that the healthcare system was ill prepared or incapable of caring for their parent, in addition to the caregiver themselves feeling ill prepared to care for their parent. Caregivers with family members in long-term care described feeling frustrated with supervision their family member received, and both types of caregivers described feeling helpless and uncertain while caregiving. These feelings might increase the caregiver's risk for developing compassion fatigue. Therefore, changes need to be made to simplify how the caregivers interact with the healthcare system and caregivers need to be made to feel a greater sense of control in the situation. Participants in the larger qualitative study of this dissertation were all given a two-page handout (Appendix C) where one page listed all of the support groups in the local area and the other page was a list of resources, including both local and online resources, where caregivers could find information. While this handout did not provide all of the information a caregiver might need to know, the handout provided enough information to direct caregivers where to go to find what they might need. Providing caregivers with a more detailed handout or a book of information might overwhelm them, but a brief handout helps caregivers figure out where to go next and offers them a sense of control in a situation where caregivers often felt helpless. The handouts were

well-received by caregivers in the study and even though many of the participants were recruited through support groups, they had not been provided a list of resources such as the handout.

Another important implication for practice that arises from this dissertation is the prevalence of perceived suffering and the caregivers' desire to protect their parents. Health care providers, and nurses in particular, are in an opportune position to address care recipient suffering and it is important to note that most of the suffering expressed by the caregivers related to psychological or existential suffering and very little was physical suffering. Therefore, assisting caregivers to find meaning in the life of the care recipient might reduce the caregiver's perception of existential suffering. Similarly, allowing the caregiver to focus on meaning in the life of the care recipient helps foster the relationship between the caregiver and care recipient. The caregiver might be able to find additional sources of satisfaction when the relationship between caregiver and care recipient is brought to the forefront. Most caregivers in this dissertation who expressed having a positive relationship with their parent prior to caregiving were able to find satisfaction and validation in caring for their parent and this was an important protection against compassion fatigue.

5.7 Conclusion

This dissertation was the first study to explore the concept of compassion fatigue in adult daughter caregivers for a family member with dementia. To accomplish this, the established model of compassion fatigue was tested and findings from this dissertation supported the development of a revised model of compassion fatigue applicable to family caregivers. This revised model (Figure 6) incorporates the contributing factors and moderators of compassion fatigue found in family caregivers and the model proposes revised characteristics and outcomes of compassion fatigue. In

addition, the revised model addresses several previously identified limitations with the existing model used to guide prior research on compassion fatigue, namely the understatement of the importance of relationship quality and empathy as moderators for, not causes of, compassion fatigue (Sabo, 2011). Findings from this dissertation also suggest new areas for research, specifically with all dementia caregivers and caregivers who do not utilize formal or informal support. Additional value from this dissertation derives from the detailed explanation of previous relationship quality, empathy, and caregiving experience. This dissertation is one of a few qualitative studies on compassion fatigue to provide this level of detail and serves to anchor future research on compassion fatigue in all family caregivers.

The next step for research on compassion fatigue should be a mixed-method, longitudinal study of compassion fatigue in a broader population of family caregivers for older adults with dementia. This future study would test the revised model and allow for definitive answers to questions raised in this study on the impact of the perception of suffering, importance of faith, the prevalence of depression, and the use of support in this population. Combining qualitative data with quantitative measures of known concepts from the model (perceived suffering, empathy, sense of satisfaction, depression, support) should provide a more complete picture of compassion fatigue in a broader population and enable researchers to develop more targeted interventions. The longitudinal aspect of the study would likely capture compassion fatigue as it develops and enable researchers to describe the trajectory of compassion fatigue.

Appendix A

Field Note: The interview took place in the participant's home in the evening after dinner, at 7pm. The home was cozy and it was unusually cold out and we talked about the weather when I first arrived. She offered me food and drink, but I declined, having just eaten dinner at home. We sat in the living room, her in a chair and me on a couch in the very front room of her home. Her husband and mother were both home during the interview and I met her husband when I arrived. He was White, but spoke fluent Spanish and spoke to his wife in Spanish after I came; I wonder why he did this since she is fluent in English? Maybe the speak Spanish in their home all the time since her mother is Spanish-speaking. I was not introduced to her mother during my time there. She also had 2 small puppies that were around and I met when I first came, but the spent the rest of the interview with her husband and mother in another room. After the interview, the participant left the room to go and get a picture of her and her mother, which she brought out and shared from her wedding day. After this, she went to get a purse her mother gave her when she was a teenager for a dance. It was a white, fancy purse that she had kept for over 40 years. She was storing it in a plastic bag and said she wanted to do something with it. I told her my mother-in-law had something similar that she had framed and it now hangs on the wall so they can see it all the time. She said the purse was the first really nice things she had and it was from her mother, which is why she's kept it all this time. I was surprised she never introduced me to her mother, especially knowing she was home and still awake and after she shared pictures of her.

The participant was a middle-aged Hispanic woman who was friendly and warm towards me. She said she had never spoken really about her story with anyone before and said she had also never gone to a support group. We shook hands when I arrived and when I left, though I did not say goodbye to her husband. She was referred

to me, again by a member of my dissertation committee, though they did not know one another. It was a friend of a friend and I was thankful to have a Hispanic woman speak with me.

Appendix B

Interview Guide

Opening Question: Please tell me about your experience caring for your mother/father?

Probes to address exposure to suffering, empathic ability, empathic concern:

- In what ways do you think your mother/father is suffering?
- Do you see this illness as difficult for your parent?
- What is it like for you when you think your mother/father is suffering?
- How often do you think about what your mother/father is going through?
- How would you describe your motivation to address your mother/father's suffering?

Probes to address detachment, sense of satisfaction:

- What brings you pleasure in caring for your mother/father?
- Do you ever feel the need to distance your self? If so, how has that changed over time?

Probe to address traumatic memories:

- In your caregiving experience, are there events from your past that keep coming back to you and cause you distress when you think about them?

Probes to address other life demands, burden, caregiver strain:

- What has been the impact of caring for your parent on your time/ability to get out/friendships/feelings?
- Do you feel like you have lost control of your life since your mother/father's illness?
- Do you feel stressed between caring for your mother/father and trying to meet other responsibilities?
- Do you feel that you have difficulty in performing your role as a caregiver?

Probes to address helplessness, hopelessness, apathy, avoidance, depression:

- To what extent do you feel helpless in this situation?
- Do you feel less hopeful about the future?
- How has your concern changed over the course of caring for your mother/father?
- Do you feel depressed?

Probes to address decreased relationship quality:

- Please tell me about your relationship with your mother/father before you were a caregiver?
- How has this relationship changed?

Appendix C

Resource List

Eldercare Locator www.eldercare.gov 800-677-1116
Can assist you in finding the local information and referral agency for your community.

Full Circle of Care www.fullcirclecare.org
Although this is a local information and referral website for Wake, Durham, Orange, and Chatham counties, several regional, statewide, and national links can be found here under the alphabetized "Topic Index" (left hand side of the page).

Duke Family Support Program www.dukefamilysupport.org 919-660-7510
Source for help with Alzheimer's, memory disorders, and elder care decisions. Serves families and professionals concerned about or caring for persons with memory disorders in North Carolina, and Duke employees seeking help with elder care decisions.

Alzheimer's Association www.alz.org Helpline 800-272-3900
Local chapters, support group information, education programs, and online resources.

Alzheimer's North Carolina www.alznc.org 800-228-8738
Support group information, education, and information.

Association for the Home and Hospice Care of NC
www.homeandhospicecare.org 800-999-2357
Lists home health agencies and hospices by county including Medicare certified and private agencies.

Benefits Check Up www.benefitscheckup.org
Information regarding existing federal, state, and local programs available to older adults who need help with paying for prescription drugs, healthcare, utilities, and other basic needs.

SHIIP-NC www.ncdoi.com/SHIIP 800-443-9354
Senior Health Insurance Information Program counsels Medicare beneficiaries and caregivers about Medicare, Medicare supplements, Medicare Advantage, Medicare Part D (prescriptions), and long-term care insurance. Counselors offer free and unbiased information regarding Medicare health care products. Also help with recognition and prevention of Medicare billing errors, possible fraud, and abuse.

Geriatric Evaluation and Treatment (GET) Clinic 919-620-4070
http://www.geri.duke.edu/index.php?option=com_content&view=article&id=59&Itemid=57
The GET Clinic provides service and resources to older adults and their families. The GET Clinic offers medical evaluation and treatment, cognitive and psychiatric evaluation and treatment, social evaluation and counseling, and level of care consultation.

NC Neuropsychiatry http://www.ncneuropsych.com/index.html 919-785-5055

NC Neuropsychiatry is primarily a consultation and evaluation clinic. The clinic specializes in cognitive, behavioral or emotional problems related to a medical or neurological condition.

Support Groups

County	City	Date	Time	Contact Number	Contact Name
Chatham	Pittsboro	3rd Mon	6:00 PM	919-542-4512	Phyllis Reid
	Siler City	3rd Wed	4:00 PM	919-542-4512	Phyllis Reid
Cumberland	Fayetteville	3rd Tues	2:00 PM	910-615-1633	Sam Hutchison
	Fayetteville	3rd Wed	12:30 PM	910-484-7200	Patricia Wood
Durham	Chapel Hill	4th Thurs	6:00 PM	919-929-5850	Allison O'Shea
	Durham	Last Thurs	6:30 PM	919-660-7510	Bobbi Matchar
	Dtrs & Dtrs-in-law	Last Wed	12:00 PM	919-660-7510	Bobbi Matchar
	Durham	1st Sat	11:00 AM	919-423-8498	Cordelia Holloway
	Durham	4th Tues	10:30 AM	919-660-7510	Lisa Gwyther
Lee	Sanford	1st Thurs	2:30 PM	919-776-0501 x2230	Judi Womack
Orange	Chapel Hill	3rd Thurs	2:30 PM	919-968-2087	Pam Tillett
	Hillsborough	1st Tues	4:00 PM	919-968-2087	Pam Tillett
Wake	Cary	3rd Wed	6:00 PM	919-852-1355	Phyllis Green
	Cary	3rd Thurs	6:30 PM	919-465-0356	Trudy Croxton
	Cary	4th Mon	11:30 AM	919-462-3983	Theresa Trimble
(FTD	Cary	3rd Tues	7:00 PM	919-796-5752	Tayloire Queen
caregivers)	Cary	3rd Mon	10:00 AM	919-465-0332	Joe Dunbeck
	Cary	2nd Thurs	6:00 PM	919-462-9147	Stephanie Sanderoff
	Cary	2nd Mon	10:00 AM	919-447-4494	Emily Smith
	Fuquay Varina	1st Tues	6:30 PM	919-363-2484	Frances Howard
	Fuquay Varina	3rd Tues	2:00 PM	919-363-2484	Frances Howard
	Garner	3rd Thurs	6:30 PM	919-772-0018	Donna Gould
	Alz NC Office	1st Tues	6:30 PM	919-832-3723	Melanie Bunn
Raleigh	Alz NC Office	2nd Mon	10:00 AM	919-832-3723	Dee Dee Harris
	Alz NC Office	1st Mon	7:00 PM	919-832-3723	Nancy Broadwell
(FTD	Alz NC Office	Call for	Call for	919-832-3723	Dee Dee Harris
caregivers)	Alz NC Office	Info	Info	919-832-3723	Nancy Broadwell
(early stage	Edwards Mill	1st Wed	10:00AM	919-787-0777	Lakisha Fields
indiv)	Falls of Neuse Rd.	4th Thurs	7:00 PM	919-847-4047	Trenna Perkins
(early stage	Lake Wheeler Rd.	1st Tues	7:30 PM	919-832-3007	Sue Price
indiv)	Lead Mine Rd.	1st Wed	4:00 PM	919-518-8941	Shannon Graham
	Newton Rd.	2nd Tues	7:00 PM	919-848-0303	Rachel Strauss
	Sawmill Rd.	2nd Mon	7:30 PM	919-848-7083	Phyllis Mayo
	Spring ForestRd.	3rd Wed	4:00 PM	919-981-6100	Zona Chagwiza
	Leesville Road	1st Wed	1:00 PM	919-847-8205	Carol Gault
	Leesville Road	3rd Wed	7:00 PM	x 269	Carol Gault
	W. Edenton St.	2nd & 4th Wed	4:00 PM	919-832-7227	Joseph Bukowski
	Wake Forest	4th Tues	7:00 PM	919-554-0124	Marty Edwards
	Zebulon	3rd Thurs	6:30 PM	919-269-9512	Melody Hocutt

Appendix D

Demographic Data Sheet

Instructions: Please answer each item below

When is your date of birth?		_ _ / _ _ / _ _ _ _
Are you of Hispanic or Latino ethnicity?	Yes No	☐ ☐
What racial group describes you best?	White or Caucasian Black or African American American Indian or Alaska Native Asian or Pacific Islander Other	☐ ☐ ☐ ☐ ☐
What is your marital status? (Choose one)	Married Not currently married – Widowed Not currently married – Divorced Co-habitating long-term partner Single, never married	☐ ☐ ☐ ☐ ☐
Are you currently employed?	Yes No	☐ ☐
IF EMPLOYED: How many hours per week do you work?		_ _
How many people reside in your household, INCLUDING YOURSELF?		_ _
How many children do you have?		_ _

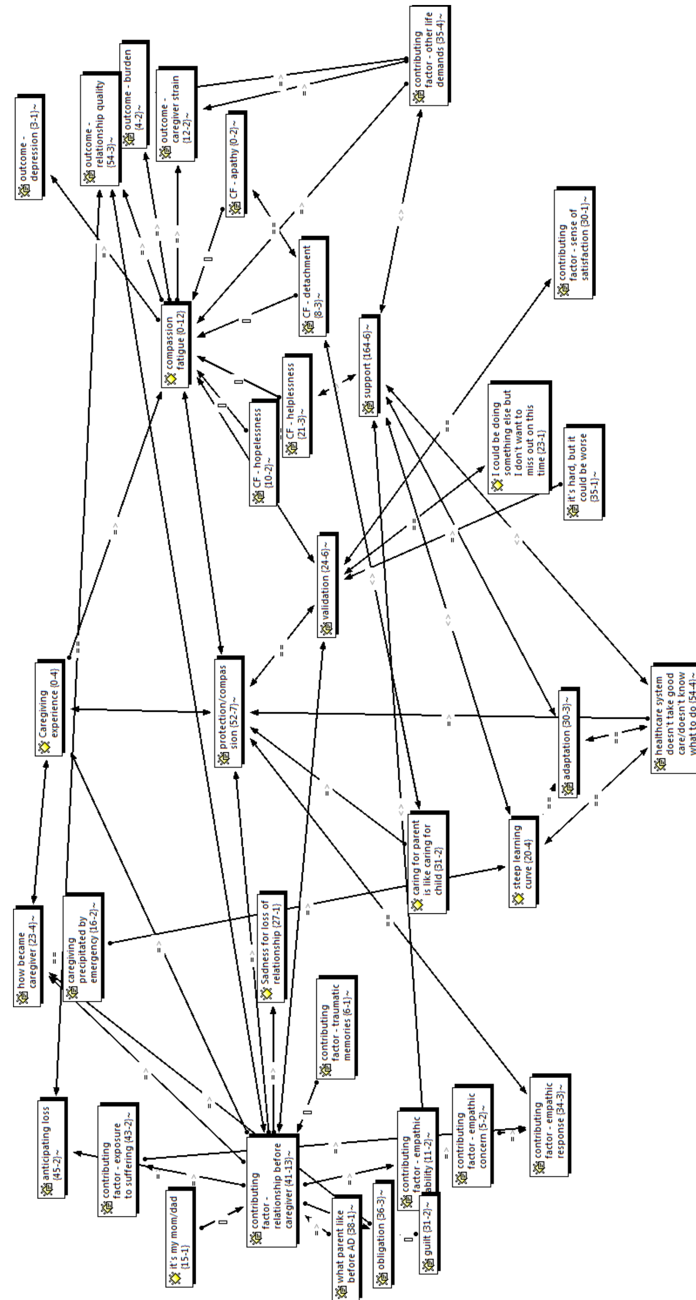
If yes, do they reside in your household?	Yes No	☐ ☐
What are the ages of your children (whether they live with you or not)?	___________ ; __________ ;_________ ___________ ; __________ ; _________	
What is your relation to your parent?	Biological daughter Adopted daughter Step-daughter Daughter-in-law	☐ ☐ ☐ ☐
How many years have you been caring for your parent?		_ _
Do you provide care for anyone else?	Other parent or parent-in-law Other family member Friend Coworker Neighbor	☐ ☐ ☐ ☐ ☐
How many hours per entire week (Sunday to Saturday) do you spend providing care for others (including your parent)?		_ _

Appendix E

Code	*Exposure to Suffering
Detailed Description	Experiencing the suffering of the parent through direct exposure
Inclusion Criteria	Physical, spiritual/existential, or psychological suffering of parent
Exclusion Criteria	Does not see parent suffer
Typical Exemplars	Sees that parent is upset when can't remember things
Atypical Exemplars	
Close but no	
Code	Family Support
Detailed Description	Help or lack of help in caregiving from family members
Inclusion Criteria	Things family members do or do not do to help caregiver
Exclusion Criteria	Help from outside family
Typical Exemplars	Sister helps watch on weekends, husband helps, children help
Atypical Exemplars	
Close but no	Other Support
Code	My Life Has Had to Be Cut
Detailed Description	Trajectory of life has changed/stopped since becoming a caregiver
Inclusion Criteria	Plans for life changed/stopped since caring
Exclusion Criteria	Life continues as had been with small modifications
Typical Exemplars	Stopped working, moved to different city
Atypical Exemplars	Not married yet
Close but no	
Code	Parent Doesn't Know Who is Caring
Detailed Description	The parent has no idea who is taking care of them, could be a stranger, could be the daughter. May recognize the daughter as someone they know, but not as their daughter.
Inclusion Criteria	Parent does not know daughter is caregiver
Exclusion Criteria	Parent recognizes caregiver
Typical Exemplars	
Atypical Exemplars	
Close but no	
Code	Adaptation
Detailed Description	Actions taken or systems put in place to help caregiver care for parent, changes make to life to accommodate being a caregiver
Inclusion Criteria	
Exclusion Criteria	
Typical Exemplars	Schedule, lights in hall, chime/bell on door
Atypical Exemplars	
Close but no	

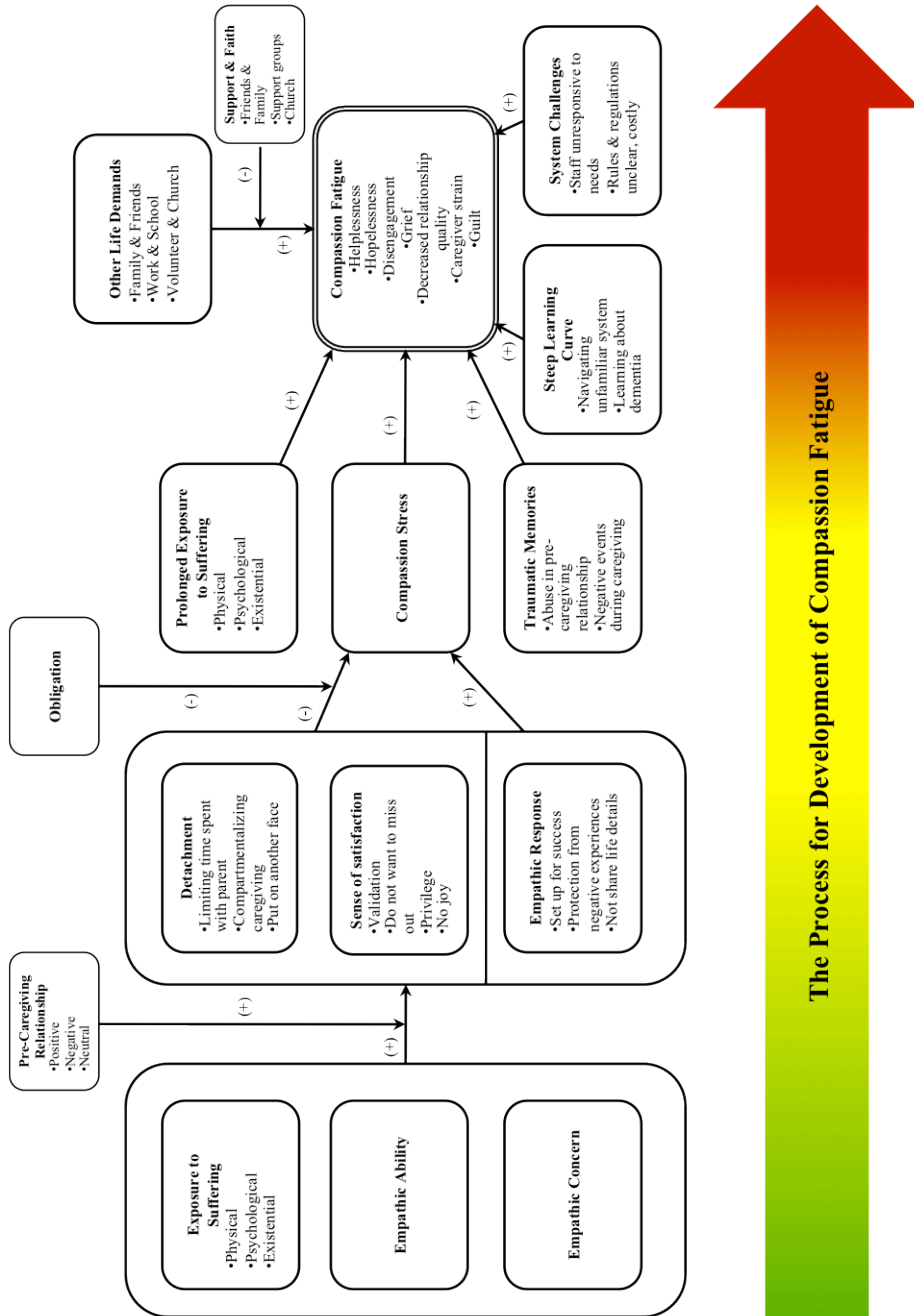
Appendix F

Network View



Appendix G

Revised model



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Biography

Jennifer Rebecca Day was born in Livingston, New Jersey on April 2, 1978 to Dr. Harry F. Ervine, Jr. and Jean Cooney, and she was also raised by her step-father, Gary Cooney. Jennifer is married to Kevin Day and they have two sons, Conor and Oliver. She received her Bachelor of Arts in May, 2000 from the University of Virginia and her Bachelor of Science in Nursing from Johns Hopkins University in May, 2005. Jennifer is a doctoral candidate at Duke University School of Nursing. She is first author of two peer reviewed articles "Compassion Fatigue: An Application of the Concept to Informal Caregivers" in *Nursing Research and Practice* and "Fall Prevention Through Patient Partnerships" in *The Nurse Practitioner*, and a manuscript in review "Compassion Fatigue in at-Home Adult Daughter Dementia Caregivers: A Pilot Study" in *Geriatric Nursing*. She co-authored "Studying the Clinical Encounter with the Adaptive Leadership Framework" in *Journal of Healthcare Leadership*. Jennifer was awarded the Ruth L. Kirschstein National Research Service Award for pre-doctoral trainees from the National Institutes of Health, the Leadership in an Aging Society Award from the Duke University Center for the Study of Aging and Human Development, and she received funding to conduct a pilot study from the NIH Roadmap Scholarship/CTSA.