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Walden University 2023

#### Abstract

Lived Experiences of Spousal Caregivers of Post-9/11 Combat Veterans

by

Rebecca Brown-Tuyishimire

MS, Capella University, 2012

BS, Lindsey Wilson College, 2005

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Human and Social Services

Walden University

November 2023

#### Abstract

The purpose of this transcendental phenomenological study was to describe spousal caregivers' lived experiences of transitioning to primary caregivers for post-9/11 combat veterans and their susceptibility to compassion fatigue. Figley's compassion fatigue theory guided this study and was essential in answering the research question: How do military spouses describe their experiences with transitioning to the primary caregiver role for post-9/11 veterans? Six spousal caregivers described lived experiences involving this topic. While the study was open to male and female caregivers, only female spousal caregivers participated. Data was collected from four participants via Zoom semistructured interviews; two participants filled out interview questionnaires and were member-checked. Data analysis was performed through four steps: immersive engagement, inductive qualitative content analysis, thematic analysis, and Colaizzi's seven-step analytic process. The study resulted in three themes and six subthemes which all impacted spousal caregivers' susceptibility to compassion fatigue. Study findings reveal that few social and medical supports were available for spousal caregivers to properly transition to their roles as primary caregivers for post-9/11 combat veterans. Results further suggest that improving social determinants of health, specifically economic stability, education access, and quality, healthcare access and quality, neighborhood and built environment, and social and community context is necessary to reduce spousal caregivers' susceptibility to compassion fatigue.

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# Dedication

The research project is dedicated to military spouses, and caregivers, past and present as they are the backbone on which their families, military community, and residential community depend.

## Acknowledgments

"It takes a village," is an age-old mantra from my Appalachian culture, and what guided my journey. For the past five years, I have had to nurture and cultivate this project, with the help of my village. I couldn't see the light at the end of the tunnel. When the pandemic hit, it really tested my ability to endure. However, my village-near and far helped me overcome every obstacle and kept me on course. Thank you to Theo, mother, father, bonus mom, siblings, in-laws, aunts, cousins, uncles, decedents of the Brown, Payne, and Honaker family, nieces, nephews, close circle of friends, Dr. John Gakwaya, Dr. Robin Ellert, Dr. Anna Nikki Douglas, Ms. Brandy Turner, colleagues, and associates. Your prayer has sustained me throughout this process and every event in my life. I am forever indebted to the six brave spousal caregivers who shared their lifechanging stories. I am hopeful that this research study will encourage the powers that be to spring into action. Lastly, thank you to Dr. Kecia Freeman, Dr. Andrew Carpenter, and Dr. Sandra Harris, your contributions and insight to helping me complete this study are invaluable. Finally, to the Creator of all things, this journey would not have been possible without answered prayers, guidance, hope, faith, and strength.

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#### Chapter 1: Introduction to the Study

#### Introduction

In 2018, the United States of America (U.S) had 4.1 million veterans after September 2001, and 41% of those veterans reported a service-connected disability (Bureau of Labor Statistics [BLS], 2019). Long-term care needs, extensive rehabilitation, and restorative care are necessary to address for civilian healthcare providers be prepared to treat this population (Elliott et al., 2020). Spouses are an essential resource for injured veterans; care provided by spousal caregivers can help promote faster recovery and save millions in healthcare costs (Wilcox, 2019). However, cost savings pale compared to health problems that caregivers experience (Wilcox, 2019).

Some spouses have transitioned to primary caregivers to support the health and wellness of post-9/11 combat veterans. Although looking after others in need is a loving and selfless endeavor, performing duties can impact spousal caregivers who work to ensure the wellbeing of post-9/11 combat veterans (Hastings et al., 2020). This transition from partners to caregivers can lead to declining health, independence, and freedom due to providing daily care for their loved ones (Sun et al., 2021). Extensive demands of caregiving often harm the physical and psychological wellbeing of spousal caregivers (Irfan et al., 2017). Spousal caregivers often begin caregiving without adequate information or training and are frequently expected to provide high-quality care without help from healthcare professionals (Saimaldaher & Wazqar, 2019). Thus, they may be at increased risk of compassion fatigue. Compassion fatigue is emotional strain related to

working, assisting, and caring for individuals with disabilities over an extended period (Crowe, 2016).

Discussions on how to care for post-9/11 wounded, injured/ill, and sick veterans have been a mainstay in military caregiving literature and within government agencies, military service organizations, veteran service organizations, and other professional agencies. Despite military spouses' central influence on service members' overall health and well-being, very little research has examined spousal caregiving for post-9/11 combat veterans from these spouses' perspectives. Moreover, their susceptibility to compassion fatigue because of caregiving has been absent from military caregiving literature.

Chapter 1 includes an introduction to issues faced by spousal caregivers of post-9/11 combat veterans, an identification of the problem, and description of the gap in knowledge in the discipline. Next, the problem, focus of the study, purpose of the study, and research question are addressed. Chapter 1 also includes information about Figley's compassion fatigue as well as the nature of the study, definitions, assumptions, scope, delimitations, limitations, the study's significance, and its contribution to military caregiving literature.

#### **Background**

Since September 2001, the U.S. military has been in military operations and combat in the Middle East (Carlozzi et al., 2018). Advances in combat medicine, technology, and healthcare have allowed more service members to survive battlefield injuries than in previous wars (Wilcox, 2019). However, these combat veterans are returning from deployment with injuries that require a great deal of care. Veteran spouses

often assume caregiving duties for injured servicemembers. Spousal caregivers are an essential resource to post-9/11 combat veterans as they provide them with essential emotional, practical, and medical care, and are critical to the sustainability of the U.S. healthcare system (Shaffer & Nightingale, 2019). Caregivers devote a continually increasing level of time, energy, and attention to managing veterans' physical, cognitive, and mental health challenges (Poyner-Del Vento et al., 2018). While caring for combat veterans, spouses may incur negative psychological, physical, mental, and emotional impacts due to caregiving. Spouses may have a difficult time creating boundaries between personal care and providing caregiving (Strong, 2018).

Many spousal caregivers report they derive significant emotional and spiritual rewards from their caregiving roles, but they may also experience physical and emotional problems directly related to stress and demands of daily care (Roberts & Struckmeyer, 2018). Given multiple challenges of caring for combat veterans, many spouses may experience compassion fatigue (Nolte et al., 2017). Typically, caregivers have deep empathy and lack the ability to disengage from caregiving, resulting in physical, emotional, and spiritual distress (McWilliams, 2020). The more empathetic the spousal caregiver, the more vulnerable they are to stress and development of compassion fatigue, especially if they cannot effectively regulate their capacity to empathize and empathic feelings (Duarte et al., 2016).

#### **Statement of the Problem**

Spouses of combat veterans experience various negative psychological symptoms brought on by long-term exposure to the combat experiences of active-duty service

members (Cobos, 2020). Spouses experience changes because of assuming the role of caregivers; they may need to change jobs, reduce their work hours, or leave the workforce entirely (Hinton, 2020). Spouses of combat veterans often surrender some autonomy when tending to the veteran's medical needs and move closer to medical treatment facilities or supportive family members (Hinton, 2020). Often, caregivers are ill-prepared to assume physically and emotionally demanding roles (Ferrell & Whittenberg, 2017).

According to Ramchand et al. (2014), there are approximately 5.5 million military caregivers in America, and only about 20% of those caregivers provide care to combat veterans who served in at least one post-9/11 war or military excursion. Post-9/11 caregivers are younger than civilian caregivers, with an average age of 30 years (Ramchand et al., 2014). The chances of developing depression for spouses caring for combat veterans are four times higher than civilian caregivers (Ramchand et al., 2014). Depression often negatively impacts the health and social functioning of spouses, which can manifest as compassion fatigue and may compromise the care and wellbeing of veterans.

Many studies on compassion fatigue have focused on nurses, mental health professionals such as clinical psychologists, counselors, psychotherapists, psychiatric social workers, psychiatric nurses, educators, police officers, and other caregiving professionals. Because these frontline responders often respond to potentially traumatic events or incidents and are required to help traumatized individuals as part of their duties,

they are often the most researched groups of caregiving professionals among trauma researchers.

Issues predisposing nurses, mental health professionals, educators, and police officers often parallel military spousal caregivers' caretaking experiences. The health of spousal caregivers is crucial to sustaining care for veterans (Jacob et al., 2020). The nature of married relationships makes post-9/11 spousal caregiver experiences different from post-9/11 military caregiver experiences. This study includes perspectives and lived experiences that can catalyze future studies.

#### **Purpose of the Study**

The purpose of this study was to explore the lived experiences of spouses serving as caregivers for post-9/11 injured combat veterans. A qualitative design was most appropriate for this study. Rahman (2016) noted qualitative research is used to produce thick and detailed descriptions of participants' feelings, opinions, and experiences and interpret meanings of their actions. The qualitative approach is used for a holistic view of human experiences in specific settings; this includes the study of individual cases or events as well as different people's voices, meanings, and events. Through qualitative research, researchers discover participants' inner experiences. The qualitative research design has a flexible structure, allowing for easier understanding of complex issues.

#### **Research Question**

The aim of this qualitative study was to explore lived experiences of military spouses who transitioned to primary caregivers of post-9/11 combat veterans. This

study's research question was: How do military spouses describe their experiences with transitioning to the primary caregiver role for post-9/11 veterans?

#### **Conceptual Framework**

The conceptual framework is used to define and justify the research question, methodology, and interpretations of results and conclusions (Johnson et al., 2020). This study was guided by Figley's compassion fatigue theory. Compassion fatigue is the natural consequence of caring intensely for another, which is not necessarily a problem but a natural byproduct of trauma (Figley, 1995). Compassion involves personal and emotional costs to caregivers and the energy required to provide those services since it may emerge suddenly with little warning and is acute. Figley's framework is relevant because challenges of caregiving manifest. Efforts to handle complex demands of overburdened combat veterans place extraordinary stress on spousal caregivers and can result in an inability to nurture (Finzi-Dottan & Kormosh, 2016; Sorenson et al., 2016). Given multiple challenges and demanding circumstances that spousal caregivers face caring for their wounded, injured/ill, and sick combat veterans, compassion fatigue is likely to be a far more common phenomenon than might be acknowledged by spousal caregivers (Nolte et al., 2017).

# **Nature of the Study**

This qualitative transcendental phenomenological study explored the lived experiences of spousal caregivers for their post-9/11 combat veterans. Transcendental phenomenology as developed by Husserl is a qualitative approach that involves seeking to understand human experiences (Moustakas, 1994). Purposive sampling was used to

recruit participants for this study from post-9/11 Facebook groups by garnering permission of group administrators. Through purposive sampling, characteristics of spousal caregivers were addressed which enabled the research question to be answered.

Phenomenology was the most appropriate method for this study. It is a form of qualitative research that involves focusing on studying individual lived experiences within the world (Neubauer et al., 2019). The aim of this study was to understand how post-9/11 spouses of combat veterans can be susceptible to compassion fatigue because of caretaking.

#### **Definitions**

Caregiver: Person responsible for caring for a sick or dependent person, facilitating their daily activities, or carrying out whatever is required in their daily lives (Diniz et al., 2018).

Combat Veteran: Individuals who serve in any U.S. Armed Forces (USAF) branch and experience hostilities of any level or take part in actions against enemy combatants for a certain duration because of friendly, defensive, or offensive fire military action that involves a perceived or real enemy in a post- or pre-determined combat proceeding (Veterans Authority [VA], 2020).

Compassion Fatigue: Reduced capacity or interest in empathy or the emotional, physical, and spiritual distress which results from bearing clients' suffering (Figley, 1995).

Department of Defense (DoD): The largest organization in the U.S. federal government whose enduring mission is to provide combat-credible military forces that are needed to deter war and protect the security of the U.S. (U.S. DoD, 2018).

Department of Veteran Affairs (DoVA or VA): A government department that runs programs benefiting veterans and members of their families. It offers education opportunities and rehabilitation services and provides compensation payments for disabilities or death related to military service, home loan guaranties, pensions, burials, and healthcare that includes services of nursing homes, clinics, and medical centers (U.S. DoVA, 2020).

Formal Caregiver: Individuals with professional experience providing care, including licensed professionals such as social workers, registered nurses, medical doctors, occupational therapists, and physiotherapists (Li & Song, 2019).

*Informal Caregiver:* Individuals who provide substantial services through inhome unpaid assistance to their family members and friends (Edwards et al., 2020).

*Military Caregiver:* Family member, friend, or acquaintance who provides care and assistance for or manages the care of a current or former military service member (Tanelian et al., 2014).

*Post-9/11 Veterans:* U.S. servicemembers who served after September 11, 2001 (Ramchand et al., 2014).

Spousal Caregiver/Post-9/11 Spousal Caregiver: Spouse providing care for post-9/11 veterans (Ramchand et al., 2014). In this study, the term is used interchangeably

with post-9/11 spousal caregiver, which is an individual who provides care to wounded, injured/ill, and sick post-9/11 combat veterans.

Veterans: Individuals who have served but are not currently serving on active duty in the United States Armed Forces (USAF), which includes the Air Force, Coast Guard, Marine Corps, or Navy (Ramchand et al., 2014).

Wounded, Injured/Ill, and Sick: A servicemember who has experienced injuries directly attributable to a military combat operation (Verey et al., 2016).

#### **Assumptions**

Research assumptions are what the researcher believes to be true regarding a topic (Bloomberg & Volpe, 2019). I had three assumptions prior to conducting this study. My primary assumption was that participants were honest and transparent about their experiences caring for post-9/11 combat veterans. My second assumption was that a qualitative approach was the best methodology for this study due to the need for more research about spousal caregivers of post-9/11 combat veterans. This assumption is based on the gaps in literature. My third assumption was that this study would lead to future research about adverse effects of compassion fatigue on spousal caregiving.

## **Scope and Delimitations**

The scope of this study focused on Army veterans and their spouses. The targeted population were spouses who have experienced the phenomenon of being the primary caregiver of army combat veterans of post-9/11 wars. Participants were not representative of spousal caregivers from other branches of the USAF. This qualitative phenomenological study was limited to examining lived experiences of spousal

caregivers. Participants were spouses of post-9/11 Army veterans diagnosed with combat-related injuries and primary caregivers. Only participants that met the following criteria were allowed to participate:

- 1. in a heterosexual marriage,
- 2. spouse of an active-duty Army soldier during the post-9/11 wars,
- 3. spouse is an Army combat veteran, and
- 4. transitioned to primary caregiver for their combat veteran.

The settings for these interviews took place via Zoom and email. This allowed participants comfortability and anonymity to answer the questions. The participants also resided within the United States.

#### Limitations

Limitations of any study are potential weaknesses that are out of the researcher's control (Theofanidis & Fountoukie, 2018). In any given study, potential study limitations may result from underlying theories, causal relationships, measurement errors, study settings, populations, or samples, data collection/analysis, result interpretations, and corresponding conclusions (Theofanidis & Fountouki, 2018). Thus, these restrictions may affect the study design, results, and conclusions (Theofanidis & Fountouki, 2018).

Two main categories of limitations are those that result from the methodology and issues with researchers. Methodological issues that can impact conclusions researchers can result from possible sample size, lack of available or reliable data, lack of prior research, collection of data, and self-reporting data. The first methodological limitation of the study was the sample size of spousal caregivers. Sample sizes of qualitative studies

are generally small because the intention is not to ensure that the sample reflects the population but rather that it reflects the range and scope of perspectives and experiences of different people with varying backgrounds, opinions, and conditions (Hall & Harvey, 2018). However, small samples undermine a study's internal and external validity (Faber & Fonseca, 2014). External validity is challenged when results from a study cannot be generalized to its larger population or similar population or similar populations in terms of the context, setting, participants, and time (Ross & Bibler-Zaidi, 2019). This study is qualitative and lived experiences of spousal caregivers of post-9/11 Army combat veterans may not be generalizable to spousal caregivers of post-9/11 combat veterans from other branches of the USAF.

Next, lack of data or reliable data can limit the scope of analysis and the sample size and can be a significant obstacle in terms of finding trends and meaningful relationships (Aguinis & Edwards, 2014). Compassion fatigue among spousal caregivers who transition to primary caregivers for post-9/11 combat veterans is a more contemporary and evolving problem. Lastly, self-reported data is a limitation because it can rarely be independently verified. What research participants say must be taken at face value, but it may contain biases, which are limitations (Aguinis & Edwards, 2014). The researcher's unavoidable presence during data collection, which can affect subjects' responses, is another limitation of qualitative research (Mehta, 2020). Sometimes, participants may provide biased responses by responding to questions they believe are wanted by researchers rather than their authentic responses (Ross & Bibler-Zaidi, 2019). Participants may influence data collected by changing their behavior when they are

knowingly being observed (Ross & Bibler-Zaidi, 2019). Researchers in their role as observers may also bias data, they collect by allowing first impressions of participants to be influenced by a single characteristic or impression either unfavorably or favorably (Ross & Bibler-Zaidi, 2019).

The second category of study limitations is limitations of researchers. These include access, time constraints, and conflicts arising from personal issues. First, access was a limitation for me. There was limited access to spousal caregivers of post-9/11 combat veterans or organizations that had relationships with these individuals. Next, the study was stalled by social distance restrictions caused by COVID-19. Subjectivity can impact research because biases can directly or indirectly influence data collection, handling, interpretation, and reporting, invalidating research findings (Allen, 2017).

## **Significance**

This study involved addressing lived experiences of spouses caring for combat veterans. The unique needs of post-9/11 spousal caregivers remain unaddressed in terms of policy, research, and practice. This study can provide important information to individuals, businesses, communities, civic, faith, and government leaders about how to provide spousal caregivers with appropriate resources and support to sustain their health. The study was also significant because it was focused on younger spousal caregivers for post-9/11 combat veterans. Advanced weaponry, technology, and armory have increased the survival rate of post-9/11 veterans compared to their pre-9/11 predecessors (Burgess, 2017). As a result, more wounded, ill/injured, and sick service members survive brain injuries, amputations, and other injuries compared to veterans before 9/11 (Waszak &

Holmes, 2017). In addition, spouses of post-9/11 combat veterans are younger than spouses of previous wars. Consequently, they likely care for veterans with severe injuries for more protracted periods.

The study was also significant because few qualitative studies have studied spousal caregivers of post-9/11 combat veterans. Results from this study may provide human service professionals, mental health professionals, and the military community with information about how caregiving impacts the mental, physical, and emotional health of spousal caregivers of post-9/11 wounded, injured/ill, and sick combat veterans. Findings from this study involve caregivers' experiences and their need for ongoing support as combat veterans' spouses to lessen their chances of developing compassion fatigue. Findings from this study could also provide evidence about support and care for caregivers who may already be experiencing compassion fatigue. This study is also significant because the results can lead to positive social change (PSC) by changing public policies that impact sociopolitical and economic contexts that influence spousal caregivers' lives.

#### **Summary**

Post-9/11 spouses who transition to primary caregivers for injured combat veterans have yet to gain necessary traction in literature. Thus, this specific cohort of caregivers and their unique psychological, physical, mental, and emotional needs still need to be understood. Chapter 1 included an introduction to the study, literature related to the topic, the problem, and the gap in literature. This chapter also included information about Figley's compassion fatigue theory, how the data were collected and analyzed,

definitions of key terms, assumptions that are critical to the study, boundaries and limitations of the study, and how this study can contribute to military caregiving knowledge.

Chapter 2 includes a literature review and search strategies involving current and relevant articles that are applicable to caregiving and compassion fatigue. Findings apply to spousal caregivers of post-9/11 injured veterans and their susceptibility to compassion fatigue.

## Chapter 2: Literature Review

#### Introduction

The aim of this qualitative study was to explore lived experiences of spouses who transitioned to primary caregivers for post-9/11 combat veterans. Various needs and health concerns of post-9/11 spousal caregivers remain unaddressed in literature. The caregiving role is time-consuming and includes tasks that may be mentally and physically demanding (Dassel et al., 2019). Furthermore, caregiving can lead to adverse health effects and decrease the social wellbeing and functioning of spouses. Spousal caregivers often suffer compassion fatigue when transitioning into primary caregivers for post-9/11 combat veterans.

There is a plethora of information about military caregivers of pre-9/11 wars. Few studies have focused exclusively on spousal caregivers of post-9/11 veterans, which merits further research regarding this specific population of caregivers. I focused on Figley's compassion fatigue theory and its historical context, followed by literature about five helping professions in which compassion fatigue is prominent. This literature review includes an examination of informal caregivers and their vulnerability to compassion fatigue.

# **Literature Search Strategy**

Electronic databases, EBSCO and Google Scholar, were used for this literature search strategy. Keywords and phrases were: *secondary traumatic stress (STS)*, *burnout*, *compassion fatigue*, *informal caregiving*, *nursing*, *posttraumatic stress disorder* (*PTSD*), and *spousal caregiving* through the Walden University Library.

Articles were published between 2017 and 2023 and written in English. Articles on compassion fatigue mainly focused on family caregivers, informal caregivers, nurses, animal caregivers, and child caregivers; articles on spousal caregivers of post-9/11 combat veterans were absent from literature. The seminal work of Dr. Charles Figley from 1995 onward was used to provide an in-depth historical foundation of compassion fatigue.

#### **Conceptual Framework**

The conceptual framework for the current qualitative study is Figley's compassion fatigue theory. The premises of the compassion fatigue theory is that it is a natural and disruptive byproduct of working with traumatized and troubled clients. Those who experience compassion fatigue endure emotional, physical, social, and spiritual exhaustion, which may result in a decline in their desire, ability, and energy to care for others (Figley, 1995). The compassion fatigue theory is appropriate for guiding this proposed research because it is used to explain how caregivers can experience compassion fatigue while caregiving.

Joinson (1992) studied nurses in an emergency department setting and identified compassion fatigue as losing the ability to nurture. Joinson asserted experiences of burnout explicitly presented by those in helping professions were their responses to secondary trauma rather than occupational factors. Figley built upon Joinson's foundation and formulated the concept of compassion fatigue to address adverse effects of repeated exposure to hearing details of people's traumatic experiences. Figley (1995) defined compassion fatigue as an outcome of prolonged and intense contact with patients and

exposure to continuous stress. Figley extended this concept to a combination of behavioral and emotional reactions following attempts to aid traumatized people.

Figley (1995) defined compassion fatigue as tension and preoccupation with traumatized patients via reexperiencing traumatic events, avoidance/numbing, and persistent anxiety associated with patients. It is a result of bearing witness to the suffering of others (Figley, 1995). Figley (1995) said compassion fatigue has two constructs: burnout and secondary traumatic stress (STS). According to Figley (2002), these two constructs may manifest in terms of caring professionals' decreased ability to engage with clients empathetically and compassionately.

### **Literature on Compassion Fatigue**

The literature often addressed compassion fatigue, burnout, and STS as interchangeable, overlapping, or somewhat synonymous. However, the three concepts are distinctly different. Peters (2018) defined compassion fatigue as a preventable state of holistic exhaustion that manifests as a physical decline in energy and endurance and emotional decline in terms of empathetic ability and emotional exhaustion. Compassion fatigue is triggered by prolonged professional burdens and lack of support. Those experiencing compassion fatigue experience apparent physical (feeling worn out, complaints of fatigue, aches and pains) and emotional symptoms (sense of hopelessness, frustration, and despair, feelings of incompetence, impotence, and isolation; (Nolte et al., 2017).

Burnout is emotional exhaustion, depersonalization, and reduced feelings of personal accomplishment resulting from chronic work stress. Burnout, like compassion

fatigue, results in behavioral and mood disturbances, impaired relationships, and feelings of helplessness and hopelessness (Figley, 2002). Burnout is related to occupational factors such as workload, autonomy, and reward, rather than personal relationships (van Mol et al., 2015). By contrast, compassion fatigue involves an inability to engage in or enter caring relationships.

STS is the emotional duress that results when an individual hears about firsthand trauma experiences of another. Its symptoms mimic those of PTSD. Accordingly, individuals affected by STS may reexperience personal trauma or notice increased arousal and avoidance reactions related to indirect trauma exposure. The distinction between compassion fatigue and STS often needs to be clarified. In some places, secondary traumatic stress is conceptualized as synonymous with compassion fatigue (Figley, 1995), as a sub-component of compassion fatigue, or as a broader typology of stress that includes compassion fatigue (Brown et al., 2017).

In a recent conceptual review of the empathy-based stress literature, Newell et al. (2016) present compassion fatigue as a divergent construct from secondary traumatic stress, suggesting secondary traumatic stress is a potential consequence of compassion fatigue. While burnout and secondary traumatic stress may appear similar in that caregivers suffering from either may lose the ability to care for patients, they differ in how they come about.

#### Burnout

Burnout is linked to exhaustion from chronic overwork and caring for others, whereas compassion fatigue is exposure to traumatically stressful events associated with

patients' pain and suffering (Kleiner & Wallace, 2017). Unlike compassion fatigue, burnout develops gradually with prolonged emotional and physical exhaustion, resulting in widespread apathy and disinterest in work and relationships (Todaro-Franceschi, 2019). Individuals who experience compassion fatigue can recover faster if the symptoms are recognized and managed early (Kawar et al., 2019).

Freudenberger (1974) identified burnout based on his observation that new healthcare employees who worked with drug addicts became depressed, experienced lowered energy and motivation, and developed various physical symptoms.

Freudenberger's description of burnout started to gain traction in various literature, mainly social and clinical psychology. The social perspective of burnout utilized concepts involving interpersonal relations, how people perceive and respond to others; these included detached concern, dehumanization in self-defense, and attribution processes (Maslach & Leiter, 2016). The clinical perspective also dealt with motivation and emotion but framed these more regarding psychological disorders, such as depression (Maslach & Leiter, 2016).

After Freudenberger introduced the concept of burnout, Maslach and Jackson (1981) later introduced burnout as a three-dimensional model that included emotional exhaustion, depersonalization, and a sense of personal accomplishment. Burnout usually begins at an early stage of emotional exhaustion, in which individuals feel tired and emotionally worn out (Maslach & Jackson, 1981). In turn, emotional exhaustion may lead to the depersonalization stage of burnout (Maslach & Jackson, 1981).

Depersonalization occurs when workers develop negative, cynical attitudes and feelings about their clients (Maslach & Jackson, 1981). Reduced personal accomplishment is the final dimension of burnout, which refers to the tendency to evaluate oneself negatively, particularly regarding one's work with clients (Maslach & Jackson, 1981).

Burnout is common in care work and other service-oriented jobs that depend on technical and interpersonal experience (Márquez, 2020). However, due to the demands of caregiving, burnout has become pervasive in caregiving literature. Szlenk-Czyczerska (2020) found that informal caregivers of patients with chronic cardiovascular disease had average emotional exhaustion, depersonalization, and personal accomplishment. Gérain and Zech (2021) performed a meta-analysis of burnout in family caregivers (spousal or parental) and burnout in professional caregivers (primarily healthcare). The authors found that family caregivers reported more emotional exhaustion and, to a lesser extent, depersonalization and reduced personal accomplishment than professional caregivers only reported emotional exhaustion.

However, Sharma and Kelly's (2020) survey of caregivers of spousal and family caregivers of patients with end-stage cirrhosis did not reveal any significant burnout trends. Caregivers expressed that they were happy to care for their loved one and felt no resentment or anger towards their spouse or family member. Thus, Szelenk-Czyczerska et al. (2020) and Gérain and Zech's (2021) findings of burnout among spousal or parental caregivers align with Malach and Jackson's three-dimensional model of burnout. While it is not known why caregivers of end-stage cirrhosis did not report burnout from

caregiving, it is noteworthy for researchers to explore this topic in more detail and discover why informal caregivers of other chronic diseases experience burnout.

STS

The second construct of compassion fatigue, secondary traumatic stress, is the stress resulting from helping or wanting to help a traumatized or suffering person (Figley, 1995). Secondary traumatic stress is a response to the stress of interpersonal interactions between helper and client. Secondary traumatic stress continues to be viewed mainly as a response to dealing with clients, specifically people who have been traumatized. Figley (1995) described secondary traumatic stress as an occupational hazard for persons who provide direct patient care to traumatized victims.

Secondary traumatic stress is composed of three dimensions: (a) intrusion, which refers to thoughts and images of others' trauma; (b) avoidance, which refers to a general depletion due to emotional and situational fatigue with others' pains; (c) arousal, linked to negative emotions and unpleasant conditions (Figley, 1995). Thus, these symptoms are closely related to posttraumatic stress disorder, such as intrusive thoughts, avoidance behaviors, and hypervigilance – all of which can negatively affect caregivers' well-being and ability to effectively carry out their roles and responsibilities (Figley, 1995). Essentially, professionals who work with or help traumatized persons are indirectly or secondarily at risk of developing the same symptoms as persons exposed directly to the trauma (Figley, 1995). Figley (1995) considers secondary traumatic stress and posttraumatic stress disorder to be the same phenomenon as they are virtually

indistinguishable from one another, with the caveat that symptoms are typically less severe because the individual has only experienced the traumatic event secondarily.

The role of caring for traumatized individuals has been widely recognized as having inherent risks for secondary exposure to trauma and associated distress (Whitt-Woosley et al., 2020). Whitt-Woosley et al. (2020) found that indirect exposure to child trauma at a high dose was the norm for foster parents, with primary methods of exposure being from the children themselves or child welfare workers. Hence, foster parents reported moderate to high secondary traumatic stress symptoms. Bridger et al. (2020) showed higher levels of secondary trauma, 76.5%, compared to 48% in an earlier study by Hannag and Woolgar (2018). Ratrout et al. (2020) found that 52% of the participants met the criteria for high to severe secondary traumatic stress. Roden-Foreman et al. (2017) found that emergency physicians screened positive for secondary traumatic stress with clinical levels of intrusion, arousal, and avoidance symptom clusters. Thus, consistent with research on other populations, foster carers and clinicians both experience high levels of secondary traumatic stress, which can undermine their ability to care for vulnerable populations. Research on foster parents and clinicians must investigate effective strategies to mitigate secondary traumatic stress.

## Comparing Burnout and STS

Figley (2002) suggested that secondary trauma is not the same as burnout and that each has a unique effect on a professional's well-being. Although burnout and secondary traumatic stress are defined differently, the concepts have some commonalities. Burnout and secondary traumatic stress overlap, representing similar responses to differing

environmental stressors: Burnout represents a response to occupational stress, and secondary traumatic stress represents a more personal, emotional response to traumatic stress (Hotchkiss & Lesher, 2018).

Burnout best predicts secondary traumatic stress (Malkina-Rykh, 2017). Burnout is a condition that begins gradually and becomes progressively worse. Secondary traumatic stress, conversely, can occur following exposure to a single traumatic event. The critical factor differentiating secondary traumatic stress and burnout lies in the cause of the symptoms. Symptoms of secondary traumatic stress occur as a direct result of hearing emotionally shocking material from clients. In contrast, burnout can occur because of work with any client group but in response to stressors resulting from the organizational environment or lack of personal resources (Malkina-Rykh, 2017).

In contrast to burnout, secondary traumatic stress can emerge suddenly with little warning (Figley, 1995). Additionally, and different from burnout, secondary traumatic stress is associated with a sense of helplessness, confusion, and a greater sense of isolation from supporters (Figley, 2002). While service providers may exhibit symptoms of secondary traumatic stress immediately following exposure to a traumatized client, individuals develop burnout much slower (Figley, 1999). However, there is a faster recovery rate for those suffering from secondary traumatic stress than for those suffering from burnout.

#### **Literature Review**

Compassion fatigue was identified by Joinson (1992) and expanded by Figley (1995). However, the body of research has focused heavily on the nursing profession.

Since 1995, several research and popular writings in journals and trade publications have focused on the causes, effects, prevention, and treatment of compassion fatigue in the human health care field. Articles in this review include research published since 2017 on compassion fatigue among professional caregivers, military healthcare providers, and nursing and two non-professional caregivers: military and informal caregivers.

Compassion Fatigue in Military Healthcare Providers

Military medical providers may likely experience additional unique psychological stressors, given the focus and nature of their mission (Hale et al., 2020). Despite nearly two decades of continuous combat operations, identifying and evaluating stressors unique to military medical personnel has received relatively little attention (Hale et al., 2020). Military medical providers are also at risk for developing compassion fatigue as they care for a specialized population, including armed service members, Department of Defense members, retirees, and their dependents (Best et al., 2020). Military providers face the exact demands of the modern healthcare industry as their civilian counterparts. However, the added stressors of frequent environmental changes (i.e., deployments to active war zones and change-of-duty stations), working within the limitations of rank structure, and frequent leadership changes can make military providers' professional lives even more complex (Best et al., 2020).

Rivers and Gordon (2017) found that deployed nurses to combat zones suffered from symptoms of compassion fatigue because of things witnessed and smelled: jet fuel, burning flesh, and finding a boot with a foot inside. Hughes (2018) concluded that company-grade nurses repeatedly deployed for medical support began experiencing

compassion fatigue. Similarly, research has demonstrated that civilians (Dasan et al., 2015) and military (Weidlich et al., 2015) emergency care providers report high levels of compassion fatigue or related physical and emotional distress in response to patient care. Uniquely, compassion fatigue was not related to military deployments in a study of military healthcare providers because emergency care providers are trained and equipped to cope with the stresses of trauma encountered during deployment (Cragun et al., 2016).

Compassion fatigue is a reality for military healthcare providers. Rivers and Gordon (2017), Hughes (2018), Dasan et al. (2015), and Weidlich et al. (2015) found that subgroups of military healthcare providers are susceptible to compassion fatigue. At the same time, Cragun et al. (2016) refute the findings of studies of a positive association between compassion fatigue and deployments in military healthcare providers. Additional research is warranted to examine compassion fatigue in deployed military healthcare providers.

## **Compassion Fatigue in Nursing**

Compassion is one of the core elements of nursing care. Compassion is essential for high-quality patient-centered care, reducing burnout and improving clinicians' health outcomes, well-being, and resilience (Hofmeyer et al., 2020). Nurses have an innate talent to nurture and empathize with another's suffering, connecting with their patients and personalizing care (Kestler et al., 2020). However, with continued caring in intense situations comes the risk of developing compassion fatigue over time (Pérez-Garcia et al., 2020). Nevertheless, compassion fatigue continues to be the dominant topic in nursing literature and education initiatives. For this reason, it makes no sense for nurses to

participate in programs to foster compassion because they believe being too compassionate is the root cause of their fatigue (Hofmayer et al., 2020).

Pérez-Garcia et al. (2020) examined the causes and consequences of compassion fatigue from the perspective of nurses using a hermeneutic phenomenology paradigm. Results showed that the cause of nurses' compassion fatigue was their frustration over being unable to alleviate patients' suffering. The consequences of compassion fatigue among nurses were the desire to quit the profession, feeling unfit for nursing practice, not wanting to go to work, avoiding attending to the patient at certain times due to depression, lack of emotional strength, and lack of motivation at work. Wang et al. (2020) and de Wijn and van der Doef (2020), found that compassion fatigue among nurses resulted from the lack of time and resources to provide comprehensive nursing care. The consequences of compassion fatigue, as highlighted by Pérez-Garcia (2020), are consistent with earlier studies performed by Arimon-Pagès et al. (2019) and Stenheiser (2018). Arimon-Pagès et al. (2019) and Stenheiser (2018) note that the difficulties in the performance of daily life and personal and family life can cause nurses anxiety and stress, and in the most severe cases, the desire to quit the profession. While the causes of compassion fatigue and its consequences were made clear by all the authors, interventions and strategies were absent.

Xie et al. (2020) estimated the levels, prevalence, and related factors of compassion fatigue dimension in oncology nurses. The authors' study found that oncology nurses are at high risk for compassion fatigue. Similarly, Cavanagh et al. (2020) found that compassion fatigue existed across all practitioner groups studied, and Zhang et

al. (2018) meta-analysis study concluded that compassion fatigue was high among nurses. However, the study by Xie et al. (2020) focused on psychiatric nurses in Chengdu, Hefei, and Wuhan, and the results may not apply to other work settings, cultures, and countries.

Thus, social competencies and emotions, such as empathy and compassion, are vital components of nursing (Hofmeyer et al., 2020) and crucial for informal caregivers. Compassion is essential for high-quality patient-centered care (Hofmeyer et al., 2020). However, if a nurse or informal caregiver is too compassionate, they can suffer from compassion fatigue, which can impair their caregiving abilities. Since nursing is one of the largest occupations in the healthcare sector, the nursing profession has become a central focus of research on compassion fatigue (Pehlivian & Güner, 2018). Hence, despite the commonalities between nursing and informal caregiving and their susceptibility to compassion fatigue because of caregiving, there is scant literature about compassion fatigue among informal caregivers in general and spousal caregivers. The findings from nurses suffering from compassion fatigue can be generalized to informal and spousal caregivers, which sets the framework for this study.

Nurses and Spousal Caregivers Relationship

Nurses are essential in helping family members cope with a patient's critical illness (Burns, 2019). Providing care to family members is crucial as family members play an essential role in the patient's recovery from critical illness (Burns, 2019). However, Cloyes et al. (2020) found that the nursing profession may perpetuate the role of the family caregiver as unsupported and invisible. If family caregivers are invisible in

nursing education, practice standards, and related policies, spousal caregivers will most likely be absent entirely.

The relationship between nurses and spousal caregivers must be more present in caregiving and nursing literature. However, due to the unique position of nurses to build family-centered plans of care, nurses and family caregivers are extant in the literature. Hansen et al. (2017) study of family caregivers of patients with terminal hepatocellular carcinoma found that nurses can support family caregivers by eliciting their knowledge and concerns and attending to symptom presentation interpretation and treatment challenges. Kazmer et al. (2017) found that faith community nurses could provide emotional support, outside resources, and education to help caregivers become more confident and healthier. Chimbanga (2018) opines that nurses can provide education and resources for family caregivers. However, the Community Health Nurses Associates of Canada (2020) found that community health nurses and other nurses must continue to build relationships with spouses and families through relational practices during any point of contact to ensure that spouses can discuss and feel supported during the illness while understanding their specific perspectives and expectations. Furthermore, nurses must recognize the spouse's needs in the transitioned relationship (Stewart, 2020). Having opportunities for community support networks such as supporting friendly visitor programs (Victorian Order of Nurses, 2020) and relationship building in the community for health (e.g., neighborhood driving program) will benefit the family and spousal caregivers (Stewart, 2020).

Spouses often regard caregiving as a natural extension of partnership (Torgé, 2018). At the onset of a partner's disability, spouses are more likely to be the first caregivers and often continue this role for an extended period (Torgé, 2018). As López-02Espeula et al. (2018) assert, after an illness, spousal caregivers must cope with different losses, life changes, and new challenges; the loss of previous roles and, therefore, one's identity is decisive in the transition to caregiving and dependence. Nurses should address the process through a comprehensive and integrated approach focused on transition care (López-Espeula et al., 2018). For nurse-spousal caregivers' relationship to be studied and researched for future interventions, spousal caregivers cannot be termed as family caregivers. This categorization often minimizes the role spousal caregivers play in helping their spouse recover from or adjust to an illness/injury. Furthermore, it minimizes the importance nurses play in helping spousal caregivers.

## Compassion Fatigue in Military Caregivers

Within military and mental health communities, there is growing recognition of the inherent risks associated with military service and its systemic influence on the military family's functioning and well-being (Beks & Cairns, 2018). Due to the debilitating and pervasive nature of service-related injuries, a military caregiver often takes on the roles of caregiver, head of household, advocate, and primary provider (Beks & Cairns, 2018). The most comprehensive and up-to-date examination of American military caregivers estimates that nearly 5.5 million people provide caregiving services to current and former military service members (Ramchand et al., 2014).

Increased demands associated with caregiving can have several adverse effects on military caregivers' health, well-being, and functioning (Beks & Cairns, 2018). First, the transition to caregiving often leads partners to feel that the veterans' illness or injury dictates their daily lives and contributes to the neglect of their needs, desires, and sense of self (Beks & Cairns, 2018). The pervasive nature of the illness or injury resulted in veterans' difficulty socializing, their desire to be alone, and, at times, the tendency for the veterans' symptoms to dictate the caregivers' daily activities (Beks & Cairns, 2018). Consequently, partners often experience a loss of identity and autonomy, contributing to loneliness and isolation (Beks & Cairns, 2018). Michelson and Chen (2017) echo Becks and Cain's research. Military caregivers face unique challenges such as (a) care recipients often having multiple and severe injuries or illnesses; (b) having to navigate complex health systems to obtain treatment for the veteran's multiple illnesses; (c) the invisible wounds of the returning warriors requiring high levels of emotional support; (d) military caregivers often having to provide around-the-clock care; and (e) military caregiving tends to be for extended periods (Michelson & Chen, 2017).

Abraham et al. (2020) found that post-9/11 caregivers performed different types of intangibles and largely invisible work, which primarily involved creating a new standard, keeping things calm, and suppressing their own emotional experiences to. An exploratory study performed by Moriarty et al. (2018) found caregivers, the presence of a veteran with a PTSD diagnosis, and financial difficulty—related to depressive symptoms in family members of veterans. These findings are also consistent with earlier research

studies of wives or partners of military veterans with posttraumatic stress disorder (Yambo et al., 2016).

## Compassion Fatigue in Informal Caregivers

An informal caregiver is a family member or friend in a close, supportive relationship with a patient who shares the illness experience and undertakes vital care work and emotional management (Gardiner et al., 2020). Informal caregivers significantly contribute to the national health and social systems (Barbosa et al., 2020). Despite benefits such as personal growth and meaning of life, informal caregiving can have detrimental consequences for caregivers, such as worse health outcomes (Zwar et al., 2020). One such consequence is compassion fatigue.

Compassion fatigue has become recognized in family caregivers as more responsibility for care is shifted to home (McWilliams, 2020). Approximately 43.5 million caregivers provide unpaid care to an adult or a child in the United States (McWilliams, 2020). Compassion fatigue is most frequently due to providing daily care to seriously ill, chronically ill, or dying family members and a shared pain experience (McWilliams, 2020). While providing care, caregivers may neglect their health as their health problems may seem less important than the care recipient's (Jacob et al., 2020). Moreover, caregivers may need more time or energy to attend health visits owing to the high caregiving burden and stress (Jacob et al., 2020). As a result, symptoms develop throughout caring, and they can experience various physical symptoms such as headaches, chest pain, gastrointestinal complaints, and sleep disturbance (McWilliams, 2020).

Caregiving can be both psychologically and physically taxing, and the effects can interfere with the caregivers' ability to sustain themselves in their social roles while caregiving (Cannon & Fawcett, 2018). Prolonged caregiving triggers emotional, behavioral, and physiological responses that contribute to poor psychological and physical health outcomes (Cannon & Fawcett, 2018). An existing body of literature has revealed that caregiving can affect three domains of health: physical, mental, and social health (National Academies of Sciences, Engineering, and Medicine, 2016). The following paragraphs summarize the three health domains and how they relate to informal caregiving.

## Caregiving and Physical Health

The task of caring for a person with chronic health conditions requires the caregiver to have good physical health because of the considerable physical demands involved in caregiving, which often include assisting with personal hygiene, medical needs, and dealing with the uncertain prognosis daily (Sambasivam et al., 2018). Although the importance of family caregiving in managing chronic illnesses is evident, caregiving hurts a caregiver's physical health (Corvin et al., 2017). As a result of the demands associated with caregiving, family caregivers are most likely to struggle with their declining physical health status as they age concurrently with the person, they are providing care for (Epps et al., 2019).

DePadova et al. (2019) found that the caregivers have deteriorating physical health, with the most common physical complaints including sleep disturbance, prolonged fatigue, debilitating pain, loss of physical strength, loss of appetite, and weight

loss. Similarly, Saimaldaher and Wazqar (2019) concluded that sleep disturbances were a common adverse physical health outcome of caregivers as caregivers slept inadequately or had little time to rest. Tamizi et al. (2020) found that the most crucial consequence of caregiving was a variety of physical health problems. Participants had become neglectful toward their health and experienced physical health problems such as sleep disturbances, fatigue, reduced physical activities, neck, shoulders, back, and legs pain, hypertension, arthritis, diabetes mellitus, and osteoporosis.

Jacob et al. (2020) found a positive association between informal caregiving and chronic physical conditions or physical multimorbidity in low-and middle-income countries. Jacob et al. (2020) claimed informal caregivers are at exceptionally high risk for musculoskeletal discomfort and injury, especially when engaging in activities that are physically demanding (e.g., transfers, bathing), as these activities may also increase the risk of injury and possibly osteoarthritis and lead to multiple chronic conditions.

Ainamani et al. (2020) also found that caregivers who manually lifted patients from one place to another in the hospital and at home involved repetitive use (and potential strain) of the lower back.

Cannon and Fawcett (2018) found that African Americans suffer more from hypertension, diabetes, and coronary artery diseases than their Caucasian counterparts, which places them at high risk for adverse health outcomes when involved in their parents' caregiving. Cannon and Fawcett (2018) concluded that African American caregivers are likely to have poorer health than other racial groups. However, a recent national caregiving study found that despite higher-intensity caregiving situations, Black

and Hispanic caregivers report less emotional stress and more sense of purpose than White caregivers (AARP & National Alliance for Caregiving, 2020). Black caregivers report better psychological well-being (Liu et al., 2020) and lower levels of burden and depression than White caregivers (Fabius et al., 2020); and have a culture of participation in extended families that may lead to a more positive view of the caregiver experience (Brewster et al., 2020).

Hispanic caregivers also engage in more intensive caregiving than non-Hispanic caregivers. However, there are mixed results on caregiving effects as some studies found that compared to White caregivers, Hispanic caregivers have higher depression and worse physical health (Liu et al., 2020). Indeed, high levels of familism among Hispanic/Latinx caregivers have resulted in lower rates of internalizing symptoms, and familism serves as a buffer against adverse outcomes associated with caregiving (Corona et al., 2017). The findings from these studies suggest that caregivers belonging to racial and ethnic minority groups may have adverse physical health but may choose to ignore it because of their cultural values and belief systems of caregiving.

The demands of caregiving can impact the physical well-being of caregivers.

Researchers and policymakers need to investigate strategies to improve caregivers'

physical health outcomes, such as being included in physical fitness/activity programs for the cared for and respite programs. Additional research needs to focus on how caregivers could participate in their healthcare during the onerous caregiving process.

### Caregiving and Mental Health

Mental health is a state of well-being in which an individual realizes their abilities, can cope with the everyday stresses of life, can work productively, and can contribute to their community (World Health Organization [WHO], 2018). Depression and anxiety are the world's most common mental health issues and have been caregiving's most frequently examined consequences (Kayaalp et al., 2020; Moss et al., 2019; Karabekiroğlu et al., 2018). However, the mental health of caregivers remains unaddressed in caregiving studies.

Stanley et al. (2017) found that higher levels of psychological distress are associated with poorer mental quality of life among caregivers. Similarly, Kaschowitz and Brandt (2017) reported that caregivers inside the household experienced a decline in their mental health, while caregivers outside the household reported good mental health. Zwar et al. (2018) found study participants looking after someone developed higher depressive symptoms, indicating this kind of caregiving to be psychologically demanding. Stanley et al. (2017), Kaschowitz and Brandt (2017), and Zwar et al. (2018) confirm that informal caregivers are at risk for adverse mental health. Thus, these findings are significant to this study as it helps to understand the participants lived experiences as caregivers.

Family caregivers for persons with dementia are the most significant caregivers (Zwingmann et al., 2020). Dementia is a serious and growing health problem, and since most people with dementia live at home, caring responsibilities generally fall on family members (Shi et al., 2020). Due to the expected substantial increase in the number of

people with dementia in the foreseeable future, the mental health needs of caregivers of persons with dementia or Alzheimer's disease have been robust in caregiving literature. Chen and as (2020) studied the racial/ethnic health disparities because of caring for persons with dementia or health status before becoming a caregiver. Their study found that Blacks and Hispanics, but not Whites, had poorer health before becoming caregivers for a spouse with dementia than those who did not. A spouse's dementia onset was associated with the caregiver's higher odds of depressive disorder, with no racial/ethnic variation.

According to Giordano et al. (2016), 68% of caretakers of people with multiple sclerosis experienced pathologic anxiety, and 44% experienced pathological depression, using the Hospital Anxiety and Depression Scale, along with experiencing elevated levels of fatigue, depression, and anger (Pooyania et al., 2016). Ruiz-Fernández and Ortega-Galán (2018) found that psychological disorders suffered by caregivers of persons with Alzheimer's disease included anxiety and depression. Thus, the health they perceive is deficient, and most report being dissatisfied or very dissatisfied with their health in general, affecting the quality of life, even in those caregivers who begin to take care of minor stages of the disease (Ruiz-Fernández & Ortega-Galán, 2018).

This study provides preliminary evidence that adverse mental health is associated with informal caregiving. Further research is warranted. These findings emphasize the importance of mental health assessment and intervention among family caregivers (Shaffer et al., 2017). Thus, researchers should promote the development of strategies for informal caregivers that foster mental health well-being.

## Caregiving and Social Health

Social health is the ability to accomplish potential and obligations, manage one's life to some extent despite a medical condition, and participate in social activities, including work (Lu et al., 2020). Social support and social engagement are two components of social health. Social support refers to the social resources that individuals receive from formal or informal supportive individual groups (Li et al., 2020). People are the main component of social groups, and physical and mental health is affected by various aspects of society, among which social support plays an important role (Li et al., 2020). Social engagement is also thought to promote a prosperous and healthy life (Liang et al., 2020).

There is an interaction between the burden of care and the level of social support (Li et al., 2020). Grant and Graven (2018) found that informal caregivers experienced confinement, a lack of freedom, and social isolation because of the severity of their caregiver's symptoms and inadequate time for social activities in conjunction with the caregiver role. Furthermore, mutual and fruitful relationships with family and friends declined because of loneliness and frustration experienced by informal caregivers.

Waligora et al. (2019) found that support networks are essential for sharing responsibilities and duties of caring. Waligora et al. (2019) concluded that many of these informal caregivers had difficulty maintaining social relationships with family and friends, felt isolated and alone, lacked familial and community support, and expressed a need for social support.

Kokorelias et al. (2020) found that caregivers reported changes to their abilities to participate in meaningful activities, such as having to reduce involvement in leisure activities, such as exercising, playing sports and traveling, limited interactions with family and friends, often leading to feelings of social isolation. When caregivers have a burden of care and low social support, the risk of declining care ability increases by 27.944 (Li et al., 2020). By contrast, changing the social support variable (from low to high) lowers that number to 10.188 times (Yang et al., 2018). Moreover, one study showed that social support interventions for caregivers could effectively improve their care ability (Yang & Zhao, 2018), suggesting that social support is correlated with care ability (Li et al., 2020). Soltys and Tyburski (2020) concur with the studies of Yang et al. (2018), Yang and Zhao (2018), and Li et al. (2020) and found that caregivers who experience support are healthier and have a greater sense of belonging, which improves their biopsychosocial functioning.

Social engagement is positively associated with various aspects of physical and psychological well-being in caregivers (Liang et al., 2020). Higher caregiver social engagement was associated with better self-reported health for the care recipient (Kelley et al., 2017). Griffin et al. (2017) found that having supports, such as social, family, and intrapersonal resources (e.g., social support, companionship, caregiving help, family cohesion, and self-esteem) have found to be protective against caregiving burden and poor mental health. Griffin et al. (2017) claimed little involvement with friends and relatives and lack of engagement in formal or organized activities result in social isolation, lower self-reported health and health-related quality of life, and increased

morbidity and mortality risk. Furthermore, when the social network is insufficiently supportive, feelings of loneliness may arise (van den Broek & Grundy, 2018), often resulting in the caregiver socially isolating themselves.

Too often, caregivers' social health diminishes because they become so consumed in caregiving that they neglect their social support and engagement. More studies must focus on how caregivers' social health can be positively maintained while caregiving. Research should focus on what types of social support are most appropriate for caregivers, which can improve their health outcomes, alleviate their social isolation, and potentially reduce their feelings of loneliness. Including caregivers' social health in research initiatives and policy design is essential.

### **Summary**

Figley's compassion fatigue theory was the theoretical framework for this study. The literature review suggests that compassion fatigue and its subcomponents burnout and STS are prevalent among formal and informal caregivers. However, many qualitative and quantitative studies on compassion fatigue have focused on nurses; thus, the purpose of this study is to add to the extant literature on caregiving.

Caring for wounded, sick, and ill/injured persons can increase the likelihood of developing compassion fatigue, burnout, and STS, adversely affecting caregivers, which can compromise their ability to continue caregiving. While formal and informal caregivers share similar symptomologies, informal caregivers' mental, physical, and social health can decline with more extended periods of caregiving. More research is

being dedicated to informal caregivers as their contributions to the care of sick persons are critical to medical systems.

Chapter 3 includes an introduction to the research methodology for this qualitative study regarding spousal caregivers of post-9/11 combat veterans and their susceptibility to compassion fatigue. This approach was most appropriate to address lived experiences of this specific cohort of spousal caregivers. Chapter 3 includes the research design and rationale, role of the researcher, (methodology, and issues of trustworthiness. The chapter concludes with a summary and transition to Chapter 4.

### Chapter 3: Research Method

#### Introduction

The purpose of this transcendental phenomenological qualitative study was to explore experiences of post-9/11 Army spouses who transitioned to primary caregivers for wounded, ill/injured, and sick combat veterans. This chapter includes the research design and rationale, my role as the researcher, methodology, issues of trustworthiness, ethical procedures, and a summary.

### **Research Design and Rationale**

I employed a qualitative transcendental phenomenological design. The goal of qualitative research is to gather data to describe and interpret an issue or phenomenon systematically from the point of view of the individual or population being studied (Mohajan, 2018). One advantage of qualitative research is that it allows participants to freely express their own opinions and experiences involving a phenomenon or experience using their own words (Kennedy, 2019). Qualitative research was the appropriate method for exploring experiences of spousal caregiving populations of post-9/11 combat veterans.

Phenomenology was the most appropriate for this qualitative study.

Phenomenology comes from the Greek word *phainomenon*, meaning what appears.

According to Christensen et al. (2015), the primary objective of a phenomenological study is to explicate meanings, structures, or essence of lived experiences related to a specific phenomenon. Phenomenology involves addressing perceptions, perspectives, and

feelings of people who have experienced the phenomenon or situation of interest (Giorgi et al., 2017).

Hermeneutic phenomenology involves examining individuals' lived experiences and reflections (Bynum & Varpiro, 2017). Transcendental phenomenology was selected to identify a phenomenon to explore by addressing how and what is experienced regarding the phenomenon. Furthermore, transcendental phenomenology relies on individual experiences of participants (Creswell & Poth, 2018). The phenomenon under investigation are the lived experiences of spouses who transited to primary caregiver of a post-9/11 veteran. Thus, a transcendental phenomenological study design was employed.

#### **Role of the Researcher**

The role of the researcher in qualitative research is to access the thoughts and feelings of study participants (Austin & Sutton, 2014). However, this task is challenging, as it involves asking people to talk about things that may be very personal to them (Austin & Sutton, 2014). Sometimes, the explored experiences are fresh in the participant's mind, whereas reliving past experiences may be difficult on other occasions. I am an African American female, guidance counselor with the Department of the Army. I am married to a medically retired Army veteran who completed two combat deployments and one humanitarian assignment. My husband was diagnosed with post-traumatic stress disorder and traumatic brain injury because of his post-9/11 duties, resulting in physical and mental exhaustion. Due to my caregiving experiences, there are five biases I developed about spousal caregiving. First, a spouse's sacrifice of caregiving will never be equivalent to a veteran's sacrifice in war and the injuries sustained by war.

Secondly, spouses are only transitioning to the primary caregiver because of their marital obligations, not for personal fulfillment. The third bias was that caring for the injured spouse at home means the spouse can easily balance other household and marital responsibilities. The fourth bias was that the spouse should be grateful that the veteran is alive and has survived their battlefield injuries, irrespective of the severity of the injuries. Lastly, the spouse's physical, intimate, and marital interactions should not take precedence over the caregiving needs of the veteran.

I have acknowledged my experiences of suffering from compassion fatigue while being the primary caregiver for my combat veteran husband. Since I do not enjoy caregiving, it was challenging to maintain a strong sense of objectivity, especially towards those post-9/11 spouses who have a sense of satisfaction in their caregiving duties. Furthermore, my dual identity as a counselor and a spousal caregiver complicated the study. Dual identities are not equal. Counseling Army veterans brings me great joy, while caregiving for my retired Army veteran spouse is not enjoyable. Removing my counselor hat and military spousal caregiving hat helped me remain objective, which helped the interviewees be honest about their spousal caregiving experiences. Not being objective would have undermined the successful completion of this study.

Any researcher biases not adequately addressed or errors in judgment can affect the quality of data and subsequent research results (Johnson et al., 2020). Thus, to minimize researcher bias, I was transparent and reflexive (i.e., critically self-reflective about my preconceptions, relationship dynamics, and analytic focus) about how data was collected, analyzed, and presented (Galdas, 2017). Additionally, I wrote objectively and

with sensitivity, avoided generalizations and the use of gender-specific pronouns, and did not project my personal experience onto the participants.

This research used an emic perspective. The emic perspective refers to data that are explanatory and that refer to the meanings participants themselves attach to their experience (Haapanen & Manninen, 2023). The emic approach is best described as beginning with a blank page and allowing research participants to define and explain the concepts of interest in their own words (Lituchy et al., 2017). Emic viewpoints come from participants with an 'insider' perspective on what is going on in their community that can help explain the relationship between circumstances and outcomes unknown by outside experts (Gaber, 2016). Through emic investigations, a phenomenon, not well understood could be investigated, and there was a good amount of informational uncertainty on what was happening in the military spousal caregiving community.

My role was emic because I identify as a military spouse of a post-9/11 combat veteran, paralleling the roles and experiences of the participants in this study. One advantage of being an emic researcher is I listened with an empathetic and compassionate ear to hear their experiences. In this role, I was the primary instrument of data collection. Working with Army combat veterans and being the spouse of a retired combat veteran, there was potential for researcher bias. More specifically, an emic approach could have obscured my objectivity and impartiality; however, it did not.

Researchers bring to each study their experiences, ideas, prejudices, and personal philosophies (Smith & Noble, 2014), which can contribute to researcher bias.

Understanding researcher bias is essential for several reasons. First, bias exists in all

research and is difficult to eliminate (Smith & Noble, 2014). Second, researcher bias can occur at each stage of the research process; third, bias impacts the validity and reliability of study findings, and misinterpretation of the data can have significant consequences for practice (Smith & Noble, 2014). As a researcher, I was aware of my actions, so I did not display biases or sympathy for the participants' life situations.

Within qualitative research, the researcher is the primary instrument, and therefore, the researcher must appear neutral and objective. Hence, I was transparent and reflexive (i.e., critically self-reflective about my preconceptions, relationship dynamics, and analytic focus) about how data was collected, analyzed, and presented (Galdas, 2017). Two techniques I used to manage research bias were reflexivity and bracketing. Reflexivity is an essential tool for enhancing the rigor and trustworthiness of a qualitative study (Probst, 2015). Reflexivity is essential because our position might only be clear to us, and we are sometimes unaware of our prejudices and relationship with our cultural contexts and settings (Barrett et al., 2020). Reflexivity is a continual process. As a reflexive researcher, I carefully considered and articulated to the reader my choices at each stage of the research process and considered alternative perspectives that may be at odds with mine (Barrett et al., 2020).

Bracketing is an essential tenet of phenomenology that requires researchers to set aside personal theories, research presuppositions, inherent knowledge, and assumptions as separate from what is observed in the research process (Creswell & Poth, 2018). I used bracketing to minimize researcher bias and ensured the results were grounded in the participants' experiences. Bracketing refers to the researchers' use of journal writing or

other reflexive mediums for capturing their preconceived notions, assumptions, feelings, and reactions to the data (Boles, 2018). Incorporating time and space for bracketing throughout the phenomenological study helped to bracket away as much of my voice and perceptions as possible so that when I interpreted the data, the participants' voices rang through most clearly (van Manen, 2016). Adhering to the suggestions of Grinnell and Unrau (2018), I bracketed, acknowledged, and explored my own experiences of caring for an injured military spouse. I adhered to Joe and Shillingford-Butler's (2019) strategy of personal reflection and maintaining analytic memos chronicling my reactions and initial thoughts about the data collection and analysis. I participated in reflexive journaling to make my experiences, opinions, thoughts, and feelings visible and an acknowledged part of the research process. I documented my bias, preconceptions, and assumptions, which may have negatively influenced the findings, in addition to my background and expertise about spouses transitioning to primary caregivers for their post-9/11 combat veterans. By engaging in reflexive journaling facilitated my understanding of unexpected research encounters. It improved my awareness of researcher positionality to understand interview data better, contextualize findings, and support the development of independent researchers (Meyer & Willis, 2019).

## **Ethical Implications**

A central ethical component of research design, participation, and consent involves risk assessments identifying ways research participants may be negatively affected, the likelihood and significance of potential harm, and ways to minimize potential harm appropriately (McDonald et al., 2017). Traditionally, research harms

include adverse physical, psychological, social, legal, and economic outcomes (McDonald et al., 2017). While I did not foresee any adverse physical, legal, or economic outcomes, I did believe there could be negative psychological and social harms that some participants may have to confront from discussing such a sensitive topic. Recalling traumatic or distressing events may cause psychological harm to the participants (National Research Council, 2014). Specifically, questions about transitioning to the primary caregivers for their wounded, injured/ill, or sick combat veteran may be considered offensive and invasive. Hence, this can cause short-term suffering within the specific time frame of the study and may be followed, for some participants, by an extended period of flashbacks, nightmares, reactivation of fears, or unhappy rumination (National Research Council, 2014).

To minimize risks to participants, I adhered to the three principles, or general prescriptive judgments relevant to research involving human subjects, established by the Office of the Secretary's Belmont Report (1979). These three principles included: (a) respect for persons- treat individuals as autonomous human beings, capable of making their own decisions and choices; (b) beneficence-minimizing the risk of harm and maximizing the potential benefits; and (c) justice- treat people fairly and design research so that its burdens and benefits are shared equitably.

To lessen potential conflicts of interest, I took a series of steps. First, I safeguarded the study participants' personal information by identifying them with a pseudonym. Next, I ensured I had no past or current relationships with the participants. I informed individuals about the research and ensured they gave voluntary consent before

becoming participants. Participants were fully aware of their opportunity to withdraw from the study without consequences. The sensitivity of people's information, such as their life histories, behaviors, opinions, and emotions, requires safeguarding (Azevedo et al., 2020). Audio recordings can threaten participants' willingness to participate; thus, they assured the recordings would be kept safe in a place with restricted access until destroyed (Azevedo et al., 2020).

### Methodology

# **Participant Selection Logic**

I explored the lived experiences of spouses who transitioned to primary caregivers for their post-9/11 combat veterans. Caring for an injured veteran is often the responsibility of the spouse. Therefore, the targeted population for this study was military spouses who were primary caregivers to their combat veterans. Only military spouses who fit the established criteria and have experienced the phenomenon under study could participate.

Participants for this study were recruited via post-9/11 and military Facebook groups. Purposeful sampling was used to identify spouses who transitioned to primary caregivers for their post-9/11 combat veteran. Patton (2014), the authority on purposeful samples, postulates, the logic, and the power of purposeful sampling lies in selecting information-rich cases for study. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling (Patton, 2014).

The sufficiency of data collection occurred at saturation. Glaser and Straus (1967) introduced saturation as the point in which "no additional data are being found whereby the [researcher] can develop properties of category" (p. 61). Over time, the broader term data saturation has become increasingly adopted and is often described as the point in data collection and analysis when new incoming data produces little or new information to address the research question (Guest et al., 2020). The more useful data collected from each person, the fewer participants needed (Vasileiou et al., 2018). Using purposive sampling increases the chances of a researcher reaching data saturation because the subjects obtained through this technique have rich information my qualitative study addresses (Mwita, 2022). A minimum number of participants was not established, I was confident the study goal, nature of the study population, sampling strategy used, type of data, and other influences would produce between 9-17 participants (Hennink & Kaiser, 2022). I was optimistic I would achieve saturation at 10 participants; however, due to the homogenous population within the study, saturation was achieved with five study participants.

#### Instrumentation

In qualitative research, the researcher is the primary instrument for data collection and analysis (Merriam & Tisdell, 2017). The researcher defines the meaning of data at all stages of the research process (Corbin & Strauss, 2015). Creswell and Poth (2018) caution against using instruments designed by previous researchers. Thus, as the primary data collection and analysis instrument, I used self-designed demographic surveys and semi-structured interviews with open-ended questions. The self-designed demographic

surveys in their initial form were presented to the dissertation committee to judge their appropriateness in terms of their validity and affiliation with the subject measured (Alkhawaldeh & Khasawneh, 2021). The dissertation committee suggested amendments they deemed appropriate; amendments were made and presented to the study participants in their final form (Alkhawaldeh & Khasawneh, 2021). The following sections will describe in detail the instruments used in this study.

# **Demographic Questionnaires**

Spousal caregivers who consented to participate complete a demographic questionnaire before being interviewed. I created a demographic questionnaire (see Appendix F) to understand background information about spousal caregivers. The demographic questionnaire had nine questions, including the study participant's age, years of marriage, household income range before/after caregiving, ethnic group, highest education, employment status prior to caregivers, years of service, years of primary caregiver, and number of children and ages. The questionnaire was designed to ensure it accurately described the sample of participants (Hughes et al., 2021). By describing the sample in detail, I determined the sample I recruited represented the population I wanted to study (Hughes, 2021). In addition, describing the sample's demographic characteristics would help readers to understand the sample better, to tell if the findings are generalizable, to compare the sample to other studies, and to help when it comes to replicating the research (Hughes et al., 2021).

#### **Semi-Structured Interviews**

Semi-structured interviews provide the flexibility to add real-time questions and topics to the interview (Blanford et al., 2016). Through the interview, I gained a deeper and more dimensional understanding of their responses. Interview questions were openended to avoid leading questions; thus, the participant could speak about specific incidences rather than generalizing. Background information was collected at the beginning of the interview. The starting point for the conversation was prepared questions, but follow-up questions were asked based on the participant's comments. During the interview, I adjusted to the participant bringing topics up earlier in the interview than planned. I was also prepared for the possible nervousness or discomfort that the participant may have felt about discussing the transition to the primary caregiver for their post-9/11 combat veteran. To combat this issue, I assured participants that the spousal caregiving journey was at issue, not the participants. I also was attentive and non-judgmental. At the end of the interview, I allowed the participant to provide any additional thoughts they may have had related to the interview topics. I added any information they realized they had forgotten earlier in the interview. The participants were thanked for their participation.

### Sampling

Sampling is the selection of a subset of the population of interest in a research study (Turner, 2020). Since the participation of an entire population is not possible, a smaller group is relied upon for data collection (Turner, 2020). Probability sampling draws samples from a population using random selection, with every population element

having a known (or knowable) nonzero inclusion probability (Wisniowski et al., 2020). In contrast, nonprobability sampling involves the arbitrary selection of elements into the sample for which inclusion probabilities are unknowable (and possibly zero for some population elements) (Wisniowski et al., 2020).

Purposive and snowball sampling were the two nonprobability sampling methods employed in this qualitative research study. Qualitative samples are purposive, that is, selected because of their capacity to provide richly textured information relevant to the phenomenon under investigation (Vasileiou et al., 2018). Purposive sampling allows the researcher to recruit people who can and are willing to provide the information based on their knowledge or experience with the topic or phenomenon of interest (Etikan et al., 2016). In this study, the focus was on spousal caregivers of post-9/11 combat veterans. Since spousal caregivers of post-9/11 combat veterans are a small population, they often know each other (Baltes & Ralph, 2020). The snowballing method, in concert with purposive sampling, was used. Snowball sampling works by finding a few individuals in the population, studying them, and then asking them to refer other members of the population they know (Baltes & Ralph, 2020).

### Sample Size

Limited research is available discussing a quantitative figure for sample size in qualitative research (Guetterman, 2015). Samples in qualitative research tend to be small to support the depth of case-oriented analysis fundamental to this mode of inquiry (Vasileiou et al., 2018). However, defining small sample sizes and the maximum number of participants to achieve saturation has been an ongoing debate in qualitative research.

Data saturation means collecting qualitative data to the point of closure because the study has provided maximum information on the phenomenon, and new data will yield redundant information (Moser & Korstjens, 2017).

The usually small sample size in qualitative research depends on the information richness of the data, the variety of participants (or other units), the broadness of the research question and the phenomenon, the data collection method (e.g., individual or group interviews) and the type of sampling strategy (Moser & Korstjens, 2017).

Historically, sample sizes have varied. Bertaux (1981) recommended that qualitative research be limited to a minimum sample size of 15. Morse (1994) opined that a sample size of at least six was appropriate for phenomenological research, whereas Creswell (1998) suggested a size of five to 25. However, contemporaries such as Guest et al. (2006) posit that data saturation had occurred after analyzing 12 interviews, and no new themes emerged. However, Moser and Korstjens (2017) recommend less than ten interviews for phenomenological studies. I followed the suggestions of Patton (2014), who suggests determining a minimum sample size and increasing, if necessary, to reach saturation. However, only six participants were utilized for the study. This was due to lack of responses to the recruitment flyers.

#### **Recruitment Procedures**

As an initial point of contact with veteran medical and treatment centers specializing exclusively in providing care for combat veterans, I requested to recruit participants through those organizations (see Appendix A). An informational letter was also sent to administrators of Facebook groups of post-9/11 military spousal caregivers

(see Appendix B). Seven Facebook military groups were sent an informational letter, as follows: Veteran Caregiver and Resources, Support for Spouses and Caregivers of Veterans, Military and Veteran Caregiver Research, Spousal Care Community-The Caregiver Space, Caregiver Support Group, Caregiver Resources, and Hands and Voices: Military Family Support Group. For the Facebook support groups for post-9/11 spousal caregivers that have restricted access (closed to non-members), a private message was sent from my personal Facebook account, explaining my research topic, details of the study, and asking to either join the group or if the administrator could post on my behalf. The informational e-mail to the medical and treatment and Facebook groups contained a copy of the recruitment flyer (see Appendix C), which included the criteria for participation, reasons to participate, benefits/risks, and researcher contact information.

# **Procedures for Participation**

Individuals who responded to the recruitment flyer (see Appendix C) were asked a series of questions via phone to determine if they met the criteria for the study. The informed consent form (see Appendix D) described the following: the purpose of the study, description of the research, subject participation, potential risks and discomforts, potential benefits, confidentiality agreement, compensation, voluntary participation, and authorization, right to be audio recorded, and option to withdraw from the study at any time. Also, the participants had to agree to be audio recorded. Next, potential participants could ask any questions they had about the research. After verifying that those individuals met the eligibility criteria for participating in the study, the consent form (see Appendix D) was read to the interviewee. Participants were asked for a date on which

they would be available for an interview. Participants were asked to set aside approximately 60 to 90 minutes for the interviews. Each interview began with an opening statement providing information about myself as a researcher and Ph.D. candidate and my qualifications, which built trust and encouraged the participants to share their stories. Then, I explained the purpose of the study and how the data would be stored to protect their confidentiality.

The informed consent was reread to ensure the participant was fully cognizant of the research study and their rights. I then answered any questions participants may have had about the study. The participants had to answer a demographic questionnaire (see Appendix E) regarding their age, education, ethnicity, employment status before transitioning to caregiver, and years of caregiving. The interview questions (see Appendix F) were open-ended questions that allowed the participants to expand on their experiences. After the interview, participants received a \$20 Walmart e-gift card gift card for completing the interview. Transcription began immediately after the interview.

#### **Data Collection**

Qualitative interviews were the primary tool of data collection. Qualitative research interviews are attempts to understand the world from the subject's point of view, to unfold the meaning of peoples' experiences, to uncover their lived world prior to scientific explanations' (DeJonckheere & Vaughn, 2019). Qualitative interviews unfold as an interviewer asks questions of the interviewee to gather subjective information about a topic or experience (DeJonckheere & Vaughn, 2019). These interviews give the most direct and straightforward approach to gathering detailed and rich data regarding a

particular phenomenon (Barrett & Twycross, 2018). In qualitative research, there are two different styles of interviews: unstructured and semi-structured.

Unstructured interviews, a style of qualitative interviewing, use a process that allows interviews to be entirely inductive and tailored to each participant's experience (Ravitch & Carl, 2021). These interviews do not follow a pre-specified protocol or an instrument with specific questions so that the dialogue can direct the interview as it emerges during the interview (Ravitch & Carl, 2021). While unstructured interviews offer a few advantages, researchers face three main challenges when using unstructured interviews as a data collection method (Patton, 2014). According to Patton (2014), the first challenge is that this method requires significant time to collect the needed information, especially when the researcher first enters the field and knows little about the setting. It takes time to gain trust, develop rapport, and gain access to interviewees (Patton, 2014). The second challenge for researchers is to exert the right amount and type of control over the direction and pace of the conversation; it is difficult to control the degree of directiveness of the questions and statements proposed during the conversation (Patton, 2014).

Furthermore, when the interviewee moves the conversation/interview in a not helpful direction, the interviewer will need to decide when and how to interrupt the conversation gracefully to return it to a topic of interest for the research (Patton, 2014). The third challenge is analyzing the data gathered by unstructured interviews; the questions asked in each unstructured interview are dependent on the context of the interview and so can vary dramatically across multiple interviews (Patton, 2014). Due to

the challenges of unstructured interviews, semi-structured interviews were chosen as the interview method.

The most prominent data-gathering method of qualitative research is the semi-structured interview (Johnson & Parry, 2015). The purpose of using semi-structured interviews for data collection is to gather information from key informants with personal experiences, attitudes, perceptions, and beliefs about the topic of interest (DeJonckheere & Vaughn, 2019). Researchers can also delve deeply into personal and sometimes sensitive issues (DeJonckheere & Vaughn, 2019).

Semi-structured interviews allow interviewees to express their ideas within a specific range freely (Li et al., 2019). Open-ended questions were used to gather information from participants about their experiences, opinions, attitudes, feelings, and knowledge (Thwala et al., 2018). Also, semi-structured interviews allowed for follow-up questions, probes, and comments based on the answers given by the participants (DeJonckheere & Vaughn, 2019). Through semi-structured interviews, I gathered information from key informants with personal experiences serving as primary caregivers for their post-9/11 combat veteran spouses. The interviews were audio-recorded to capture the exact words of the participants (Thwala et al., 2018).

While there is uncertainty and ambiguity in the literature over audio recording and its ability to elicit participant openness (Pell et al., 2020), this study did conduct interviews via audio recording. Audio-recorded interviews can be as powerful as face-to-face interviews to produce rich and high-quality data (Pell et al., 2020). Meeting participants in person was not feasible. Since there was no travel involved, Skype and

audio-recorded interviews were cost- and time-effective, had increased safety, and greater flexibility compared to face-to-face interviews along with reduced costs, increased safety, and greater flexibility (Drabble et al., 2016). Furthermore, in-person interviews may increase social pressure, and participants may not openly discuss their experiences (Farooq & de Villiers, 2017). Through qualitative audio recording interviews, biases and stereotyping of interviewees based on visual traits and behavior can be avoided (Farooq & de Villiers, 2017).

Qualitative telephone interviews have their advantages. However, some challenges accompany this method of qualitative interviews. Pell and et al. (2020) opined that it may be more challenging to establish a good rapport in audio-recorded interviews than face-to-face, as it may inhibit the participants from discussing sensitive and emotive issues at the start of the interview. A second drawback of qualitative audio recording interviews is the researchers' inability to respond to visual cues.

Before conducting semi-structured interviews for participants, participants were read an informed consent letter (see Appendix D) and gave verbal consent to voluntarily participate in the study. The interviewer provided a list of available times, and the participants picked the time slot to conduct the interview. Due to the sensitivity of the subject matter, the time slots were offered to participants for 120 minutes to give them extra time to describe their transition experience to the primary caregiver for their post-9/11 combat veteran. Four of the six participants completed the semi-structured interviews by Zoom, consisting of pre-interview questions (see Appendix E) and interview questions (see Appendix F), which lasted between 45 and 60 minutes. Due to

schedule conflicts, the fifth and sixth participants called me and opted to complete the pre-interview (see Appendix E) and interview questions (see Appendix F) via e-mail. The information from all six participants produced such rich information. Thus, no follow-up interview was required.

At the interview's conclusion, they were formally thanked for their participation and debriefed. I allowed them the opportunity to ask any questions or voice any concerns. I reassured participants that their names in the study would appear as a pseudonym to ensure the information would not lead to their identification or any other people, organizations, and places (Heaton, 2021) in their circle. I verified the study participants' e-mail to send the \$20 e-gift card. I also encouraged them to contact me if they were interested in reading the completed study. Although Lisa and Madelyne were unavailable for interviewing, they agreed to a follow-up interview via Zoom, in which they were debriefed in the same manner as the other participants.

The interviews were transcribed by Rev.com before being analyzed to minimize the limitations associated with the mere intuition and recall of information and individual biases (e.g., prejudices) (Azevedo et al., 2017). Furthermore, transcription allows the repeated and detailed observation of the course and the interview content, sharing this information with others, and reuse or reexamining of the data in other projects or according to another objective (Azevedo et al., 2017).

To ensure an adequate response to any setbacks along the way, I: (a) backup copies of the recordings and the original recordings were kept on different storage

devices; (b) created an identification system that allowed associating the recording file with the transcription document; and (c) stored the transcripts in a safe location.

After the preparatory phase and before moving on to writing, I learned and familiarized myself with some materials and information. Field notes from the interview were read and analyzed in detail because they contained clues and valuable information during transcribing, such as repeated recording listening.

# **Data Analysis Plan**

Data analysis is the most complex phase of qualitative research (Nowell et al., 2017). There were four steps in the data analysis plan. The first step was immersive engagement, followed by inductive qualitative content analysis, thematic analysis, and lastly, Colaizzi's (1978) seven-step analytic process. Immersive engagement is a strategy that utilizes multiple ways for the researcher to self-immerse, critically engage with, read, and analyze the data (Ravitch & Carl, 2021). To self-immerse in the data, I engaged in multiple readings with specific analytic goals for each reading (and across the readings), such as reading for power, trust, emergent concepts, and emic use of terms and concepts (Ravitch & Carl, 2021). These readings supported a researcher in exploring layers of meaning in an interview broadly and precisely as they relate to the research question (Ravitch & Carl, 2021).

The second step was the inductive qualitative content analysis. The inductive qualitative content analysis was used when there was a lack of or limited previous theories or research findings (Armat et al., 2018). This approach was most appropriate because my mind was not entirely blank at the beginning of the study; instead, I had the

research question, study aims, and pertinent assumptions, practically directing the analysis. As the analysis progressed, new categories emerged inductively, making tentative hypotheses.

The third step, thematic analysis, followed the linear, six-phase method, as suggested by Braun and Clarke (2006). However, it is an iterative and reflective process that develops over time and constantly moves between phases (Nowell et al., 2017). In the first phase, I familiarized myself with the data; the researchers immersed themselves in the data to familiarize themselves with the depth and breadth of the content (Braun & Clarke, 2006). In this respect, I read through the entire data set at least once before beginning coding, as ideas and identification of possible patterns emerged as I became more familiar with all aspects of the data (Braun & Clarke, 2006). Also, during this step, I engaged with the analysis as a faithful witness to the accounts in the data, being honest and vigilant about my perspectives, pre-existing thoughts, and beliefs, and developing theories (Braun & Clarke, 2006). The second phase, generating initial codes, began after reading and familiarizing myself with the data, having ideas about what was in the data and what was interesting about them (Braun & Clarke, 2006). This phase involved the initial production of codes from the data, theorizing activity that required me to keep revisiting the data (Braun & Clarke, 2006). Coding allowed me to simplify and focus on specific data characteristics, such as identifying essential text sections and attaching labels to index them as they related to a theme or issue in the data (Braun & Clarke, 2006). The third phase, searching for themes, was initially coded, collated, and identified across the data set (Braun & Clarke, 2006). Since I was doing an inductive approach, the

themes identified were strongly linked to the data and bared little relation to the specific questions the participants asked (Braun & Clarke, 2006).

The fourth phase of the thematic analysis was reviewing themes. This phase consists of devising the themes and then refining them. During this phase, I reviewed the coded data extracts for each theme to consider whether they appeared to form a coherent pattern (Braun & Clarke, 2006). The validity of individual themes determined whether the themes accurately reflected the meanings evident in the data set (Braun & Clarke, 2006). Any initial coding and theme inadequacies would be revealed and changed if necessary (Braun & Clarke, 2006).

In the fifth phase, I had to determine what aspect of the data each theme captured and identify what interests me and why (Braun & Clarke, 2006). For each theme, I conducted and wrote a detailed analysis, identified the story each theme told, and how each theme fitted into the overall story about the entire data set concerning the research question (Braun & Clarke, 2006). The sixth phase, producing the report, began once I thoroughly established the themes and was ready to begin the final analysis and write-up of the report, which provided a concise, coherent, logical, nonrepetitive, and exciting account of the data within and across themes (Braun & Clarke, 2006).

After the immersive engagement, inductive qualitative content analysis, and thematic analysis, I applied Colaizzi's (1978) seven-step analytic process to analyze the data. Colaizzi (1978) suggested that the researcher should read each participant's transcription several times to obtain a sense of the participant's experience. First, I incorporated Ravitch and Carl's suggestion of listening to a transcribed interview at least

four times to work toward a holistic understanding of the multi-layered nature of an individual's voice as it narrates self within a person's personal, relational, temporal, and cultural contexts.

Secondly, I extracted significant statements, sentences, or phrases that directly related to the lived experience of spouses transitioning to the primary caregiver for their post-9/11 combat veteran. The third step was formulating the meanings of significant statements. In this step, I tried to spell out meanings without imposing my perspective related to pre-existing knowledge, expectations, or experiences into the findings. To minimize the risk of imposing my perspective on the research findings, I formulated meanings with data rather than inserting meaning into the data.

The fourth step of the data analysis consisted of arranging the interpretive meanings into clusters, which allowed themes to emerge. I sought validation, avoided repetitive themes, and noted any discrepancies during this process.

According to Colaizzi (1978), the researcher should integrate all related information about the phenomenon under study in an exhaustive description. During the fifth step of the data analysis, I revisited the theme clusters to identify the dimensions of the participants' as primary caregivers to post 9/11 combat veterans. I reviewed the findings in concert with research participants to ensure richness and completeness. In doing so, I provided an exhaustive description of the lived experience of spouses who transitioned to primary caregivers for their post-9/11 combat veterans. The dissertation chairperson and a committee member confirmed the exhaustive description.

In the sixth step, the reduced statement of the exhaustive description was presented to participants to verify conclusions and development of the essence statement. If there were any noted discrepancies, I reviewed the significant statements, interpretive meanings, and themes to address the stated concerns.

#### **Issues of Trustworthiness**

Qualitative researchers mindfully employ various techniques to increase the trustworthiness of their research. Trustworthiness refers to confidence in data, interpretation, and methods used to ensure the quality of a study (Pilot & Beck, 2014). The techniques for establishing trustworthiness are credibility, transferability, dependability, and confirmability.

# Credibility

Credibility refers to the truth of the data or the participant's views and the interpretation and representation of them by the researcher (Polit & Beck, 2018). Credibility entails a faithful description of the phenomenon of interest and the generation of believable research claims (Hitchcock & Liao, 2018). Triangulation and member checking are the two most common techniques used to enhance the credibility of the research. I used triangulation and member checking to enhance the credibility of the findings from my research.

Triangulation enhanced the credibility of findings from the research on compassion fatigue amongst spouses who transition to the primary caregiver for their post-9/11 combat veteran. Denzin (1978) identified four types of triangulations used in social research: data triangulation, the use of multiple data sources in a single study;

investigator triangulation, the use of multiple investigators/researchers to study a phenomenon; theory triangulation, the use of multiple perspectives to interpret the results of a study; and methodological (or methods) triangulation, the use of multiple methods to conduct a study.

Of these four triangulation methods, data triangulation was most appropriate for this study. Data triangulation is different because it does not integrate results that show more validity; instead, it gives the researcher a better understanding of the data and information (Honorene, 2016). Data triangulation strengthened the study by increasing the validity and credibility of the data sets and information; this is further discussed in chapter 4.

Member checking and transcript review were the two techniques used to strengthen the credibility of the data. The objective of member checking was to ensure that a researcher's interpretation of the data accurately reflects the participants' intended meaning or their lived experience. Through member checking, my reconstructions were recognizable to audience members as adequate representations of their realities, allowing them to react to them (Lincoln & Guba, 1985). Lisa and Madelyne submitted their initial interviews via e-mail and were member-checked in a follow-up Zoom interview.

During the transcript review process, transcripts are returned to the participants to corroborate findings and evidence and produce new evidence the participant may not have given during initial data collection (Yin, 2018). The transcript review process allows the interviewee to clarify information, correct mistakes, and add new materials. Yin (2018) cautioned that the participants may cling to their perspectives and disagree with

the study's conclusions and interpretation, but these readers should be able to challenge a study's key findings.

# **Transferability**

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other respondents (Anney, 2014). Transferability provides evidence for the reader to assess the integrity of research outcomes (Cope, 2014). The two strategies used to enhance the transferability of findings from this research were thick description and purposive sampling.

Thick description involves the researcher providing details about all aspects of the research processes, from the data collection context of the study to the production of the final report (Anney, 2014). Thick description connotes a depth of contextual detail, usually garnered through multiple data sources, including observational field notes (Ravitch & Carl, 2021). It gives readers enough information and a depth of context to picture the settings in their minds and form their own opinions about the quality of the research and the researcher's interpretations (Ravitch & Carl, 2021). It is the qualitative inquirer's responsibility to provide basic information to their readers about when the data were collected, what type of community was involved, and who the participants were, in terms of their age, gender, race or ethnicity, and any clinical or social characteristics that might affect its transferability. The second strategy, purposive sampling, is widely used to identify and select information-rich cases for the most effective use of limited resources (Palinkas et al., 2015). Purposeful sampling involves identifying and recruiting participants most knowledgeable or experienced with the phenomenon under study

(Moser & Korstjens, 2017). Through purposeful sampling, the deliberately selected individuals and research settings helped get the information needed to answer the research question. This selection process considered the variables or qualities of potential participants that affect the contribution they could provide to the study (Farrugia, 2019). These variables were simple demographics such as age, gender, and socioeconomic status but included more nuanced aspects such as specific attitudes or beliefs (Farrugia, 2019).

## **Dependability**

Dependability refers to the consistency and reliability of the research findings and the degree to which research procedures are documented (Moon, 2016). Dependability ensures that the data represent the changing conditions of the phenomenon under study (Ary et al., 2014). To achieve dependability, researchers must ensure that the research process is logical, traceable, and documented (Nowell et al., 2017). An audit trail is the best way to ensure the dependability of qualitative research (Ary et al., 2014).

An audit trail is one of the best ways to establish dependability. It documents the study's purpose, including what was done, when, and why. The audit trail contains the raw data gathered in interviews, observations, and records of the inquirer's decisions about whom to interview or what to observe (Ary et al., 2014). By implementing an audit trail, an auditor or second party can audit the research decisions and the methodological and analytical processes upon completion of the study and confirm its findings. Daniel (2019) defined an audit trail in modern-day terminology as the researcher describing how they engaged with the entire process of undertaking the research. It requires the researcher to illustrate the research evidence clearly and document the thought processes

that led to the conclusions in a study, such as who was involved in the study, how, when, and where data was collected, and a detailed description of the analysis performed. The audit trail presented in this research included transcribed interviews, information about sampling, interview questions, insights about the data, data interpretation, and field notes about the participants' telephone demeanor, the setting, and tone.

# **Confirmability**

Confirmability is established after achieving credibility, transferability, and dependability (Guba & Lincoln, 1989). To achieve confirmability, the researcher needs to report on the steps taken both to manage and reflect on the effects of their philosophical or experiential preferences and, where necessary, ensure the results are the experiences and preferences of the research participants (subjects, respondents) rather than those of the researcher (Moon, 2016). Reporting on researcher predisposition, beliefs, and assumptions is a significant confirmability criterion and should be reported in qualitative research (Moon, 2016). Such reflexivity does not necessarily demonstrate the removal of bias but does help explain how the researcher's position can manifest in the research findings while yielding valuable insights (Moon, 2016).

#### Ethical Procedures

Protecting human subjects through applying appropriate ethical principles is vital in all research studies (Mohd Arifin, 2018), specifically in a qualitative study. In a qualitative study, ethical considerations have a resonance due to the in-depth nature of the study process (Mohd Arifin, 2018). I obtained approval to conduct the study from

Walden University Institutional Review Board (IRB) approval #11-08-21-0608826 (see Appendix G).

I followed the protocols of the IRB to ensure research involving human subjects was conducted with respect for individual choice, enacted with the most significant degree of beneficence/non-maleficence possible, protection of participants, and with appropriate oversight. Furthermore, I ensured that I reasoned through all risks and benefits and adjusted my protocols accordingly. Informed consent and all instrumentation or interview questions were in a format absorbable by potential participants, including grade level of language, jargon, and transparency. Instrumentation was appropriate for use with the identified population.

With the approval of Facebook military group administrators, I posted a recruitment flyer in the group. Participants had the option of reaching me by phone or e-mail. Once the participant contacted me, I explained the purpose of the study and data collection process. Furthermore, I informed the participants that their participation in the research was voluntary and that they may discontinue participation without penalty. The participants were made aware that the telephone interview will be audio recorded. I read them the informed consent, and participants agreed to participate in the study by saying, "Yes." Before beginning the study, participants could ask any questions regarding the study.

The anonymity and confidentiality of participants were preserved by not revealing their names and identities in the data collection, analysis, and reporting of the study findings. All participants were assigned a pseudonym to protect their real identity. The

participants' identities, including their names or any significant aspect of identity, were changed during data transcription. In presenting the study findings, the participants were referred to by pseudonyms in the verbatim quotes. Due to the sensitive nature of the study, spousal caregivers were made aware of the study's objectives and that no physical harm would result from participation in the study. Privacy and confidentiality of the interview environment were managed carefully during the telephone communication, interview session, data analysis, and dissemination of the findings. Furthermore, participants were made aware that the data would be stored confidentially, with researcher-only access, and destroyed five years after the study's publication.

I ensured that participants were comfortable giving honest answers about the subject matter. Each telephone interview was conducted individually in a quiet place to ensure minimal distractions, such as background noises, to ensure participant comfort. Ensuring a distraction-free background helped build a rapport with the participants, and they would not feel as if their identity would be compromised.

### **Summary**

Through semi-structured Zoom and audio-recorded interviews, I collected data about lived experiences of military spouses of post-9/11 combat veterans. Participants were recruited from organizations that provide medical care and treatment for veterans with mental, physical, and psychological impairments. Additionally, recruitment flyers were posted in Facebook groups for military spouses of post-9/11 veterans with the permission of administrators. To participate in the study, participants must have been spouses of post-9/11 veterans diagnosed with combat-related injuries, primary caregivers,

have access to a telephone (either fixed or mobile), and participate voluntarily. Spouses of combat veterans from pre-9/11 and post-9/11 wars who served in the Air Force, Coast Guard, Marines, and Navy, or spouses in domestic partnerships or nontraditional marriages were excluded. Six participants discussed their lived experiences involving transitioning to primary caregiver roles for t post-9/11 veterans. I ensured that telephone interview transcriptions were accurate through member checking.

In chapter 4, the results from data collection as well as information about the setting, demographics, data collection, and evidence of trustworthiness are presented. The chapter concludes with a summary.

## Chapter 4: Results

#### Introduction

The aim of this qualitative study was to understand lived experiences of spouses who transitioned to primary caregivers for combat veterans and their susceptibility to compassion fatigue by using Figley's theory of compassion fatigue. The research question guiding this study was: How do military spouses describe their experiences with transitioning to t+he primary caregiver role for post-9/11 veterans?

This chapter includes the setting, demographics, data collection, and analysis, evidence of trustworthiness, and concludes with results and a final summary.

## Setting

After acquiring approval for the research study from the IRB, the data collection process lasted between November 2021 and May 2022. I posted my dissertation topic on my Facebook (FB) page, and asked my friends to share my post on their pages. I also searched military groups on FB. After finding military groups on FB, I directly messaged the group administrator (see Appendix B) to post my research announcement (see Appendix C). After 7 months, I secured six participants who met the criteria. Participants were invited to partake in open-ended interviews via Zoom that were audio-recorded to describe their lived experiences as primary caregivers for injured post-9/11 combat veterans. Participants who could not meet via Zoom opted to fill out the questionnaire. All participants were informed of possible emotional and psychological risks before interviews. There were no gender requirements for the current study, but all participants were female spousal caregivers, and no male spousal caregivers participated.

# **Demographics**

Seven participants met the criteria of being in heterosexual marriages, spouses of active-duty Army veterans during post-9/11 wars, were current army combat veterans, and transitioned to primary caregiver roles. However, only six completed the study, as during interviews, one participant revealed she was not a full-time caregiver, disqualifying her from participating. As a result, six participants met all established criteria. Participants' ages ranged between 25 to 60 years old. There was also no gender specification for participants, but only female caregivers participated.

Each participant was given a pseudonym to protect confidentiality and identity (see Table 1).

**Table 1**Participant Demographics

Pseudonym	Age Bracket	Household Income (Before Taxes)	Ethnic Group	Highest Education	Employment (Prior to Caregiving)	Years Spouse Served in Post 9/11 Wars	Years Of Caregiving	Children &Ages
Molly	25-40	\$15-\$35k	White	Masters	Full-Time	5-8 years	Less than 5 years	1: 5 years old
Shannon	25-40	Prefer Not to Say	White	Bachelors	Part-Time	11+ years	Less than 5 years	2:1 & 5 years old
*Danielle*	40-60	Prefer Not to Say	African American	Associates	Stay-at-Home Mother	11+ years	8-11 years	2: 12 & 15 years old
Kelly	40-60	\$50-\$65k	White	Bachelors	Full-Time	11+ years	11+ years	4: 24, 22, 21 & 12 & 1 grandchild
Lisa	40-60	\$50-65K	White	Bachelors	Full-Time	8-11 years	11+ years	3: 16, 13 & 8 years old

Madelyne	40-60	\$50-\$65k	Filipino	Bachelors	Full-Time	11+	11+ years	2: 18 & 16
						years		years old

*Note*. Danielle indicated on her demographic questionnaire sheet she had been married for 20+ years, but during the audio recording, she stated she got married in 2007.

# **Participant Characteristics**

## **Molly**

Molly is between 24 and 40 years of age, has been married more than 5 years but less than 10 years, has a household income between \$15-\$35k before taxes, identifies as Caucasian, has a master's degree, and a spouse who served 5 to 8 years in post-9/11 wars. She has been caregiving for less than 5 years and has a 5-year-old son.

Molly stated that her husband had substantial injuries dating back to 2003, but the extent of his injuries is still unknown. She met her spouse in 2011 and has been his caregiver since the beginning of their relationship; thus, her life has centered on caregiving for him, with no financial or emotional support from her or his family. Although she participates in military caregiving groups, she often feels like an outcast as she was not part of his deployment process, and most military caregivers are interested in that part of the process.

#### Shannon

Shannon is a Caucasian woman who is between 25 and 40. While Shannon did not disclose her household income, she has a bachelor's degree and was employed part-time before transitioning to her role as full-time caregiver for her injured combat veteran

spouse. Her husband served more than 11 years in post-9/11 wars. She has been caregiving for him for less than 5 years. They share two children who are 1 and 5.

Shannon stated that access to care has been her most significant challenge in terms of transitioning to being a primary caregiver. There were many barriers and hurdles for her husband to get a primary care provider in the VA system. There were long wait times for him to be seen and for diagnosis. Luckily, she could get an appointment through one of the VA networks. Since her husband has PTSD and traumatic brain injury (TBI) but can still function without assistance, he is often not given extensive care. Because of regulations within the VA hospital system, the medical team would not speak to her about his condition. One nurse broke the rules and did discuss his condition, which helped her understand the complexity of care he would need.

#### Danielle

Danielle is between 40 and 60 years of age, has been married for over 20 years, has a household income of between \$50-\$65k, is African American, has an associate degree, and was a stay-at-home mother before transitioning to a caregiver for her spouse. Her spouse served more than 11 years of service in the post-9/11 wars. She has been his caregiver between 8 and 11 years and has two children, ages 12 and 15.

Danielle and her husband were high school sweethearts. Her husband served in the military for nearly 20 years and retired in 2017. However, the military spouse to military spousal caregiver was no easy journey. He was deployed three times. Danielle stated that her husband has PTSD, and he has flashbacks and nightmares constantly. She is very frustrated with the level of care her spouse receives at the VA because they cannot

treat his fluctuating symptoms. While Danielle feels the medical staff can handle the combat veteran's condition(s), they often are oblivious to the severity of the condition; leaving it untreated is dangerous. Also, Danielle feels the VA does not consider the caregiver's concerns or problems with combat veterans during treatment.

## Kelly

Kelly is between 40-60 years of age, has been married 15-20 years, and the household income is between \$50-\$65k before taxes. Kelly identifies as White/Caucasian, has a bachelor's degree, and was employed full-time before assuming the role of primary caregiver for her spouse. Her spouse served 11 or more years in the post-9/11 wars, and she has been his caregiver for more than 11 years. Kelly has four children, ages 12, 21, 22, and 24, and a 4-year-old grandchild who lives with her and her husband.

Prior to becoming a military spouse, Kelly was in the Navy. After separating from the Navy, she had two years of civilian life and married her husband, who is ten years her junior. Kelly never anticipated becoming his caregiver because he was younger than her. It is unknown whether her spouse has complete dementia or Alzheimer's disease. However, she has accepted that he will need a lifetime of care and will continue to be his caregiver.

#### Lisa

Lisa is between 40-60 years of age and has been married for 10-15 years. Her household income is \$ 50k to \$ 65k before taxes. She identifies as White/Caucasian, has a bachelor's degree, and was employed full-time before caregiving for her injured spouse,

who served 8 to 11 years in the post-9/11 wars. She has been caregiving for 11+ years and has three children with her spouse.

Lisa met her husband in 2004 while stationed in Hanau, Germany. They married in 2006 and had a two-month-old son during her spouse's first deployment. Their marriage was void of the learning stage as she navigated being a single parent, an Active-Duty Soldier, and a deployed husband. Deployment and lack of communication strained their marriage. His chronic pain and migraines worsened when he returned from deployment. She considered getting divorced during his initial reintegration. However, through life changes, she decided to navigate through his illness and become equipped with the tools needed to help him with his physical and mental challenges. While her husband is emotionally supportive, his physical limitations are taxing. A robust support system of non-judgmental family and friends has been instrumental to her mental and emotional fitness to caregiving for her spouse.

## Madelyne

Madelyne is between 40-60 years of age, has been married 20+ years, and has a household income of \$50-65k before taxes. She is Filipino, has a bachelor's degree, and was employed full-time before becoming her spouse's caregiver. Her spouse served 11+ years in the post-9/11 wars. She has been his caregiver for 11+ years and has two children.

Madelyne met her husband while she was touring Germany. Nine years later, they were married when he came to the Philippines. When her husband returned from deployment, he was almost unrecognizable. She believed he had a simple ankle fracture,

but it was an irreversible neuropathy condition. As a result, he was medically discharged from the Army and became emotionally distraught.

## **Data Collection**

# **Participant Recruitment**

The purpose of this study allowed for the exploration of the narratives on the lived experiences of spouses who transitioned to primary caregivers for their post-9/11 combat veteran. I joined different Facebook groups dedicated to post-9/11 wars. I sent a direct message (DM) to the Facebook Military Group Administrator (see Appendix B) asking permission to post my recruitment flyer (see Appendix C). Several Facebook administrators ignored my request to recruit participants from their groups. However, other Facebook administrators were pleased that I was undertaking the study. They stated I could recruit from their Facebook group, and they would also post my recruitment flyer on their personal Facebook page to elicit more recruits. After about six months, I secured seven participants who met the criteria: in a heterosexual marriage, spouse of an active-duty Army soldier during the post-9/11 wars, spouse is an Army combat veteran, and transitioned to primary caregiver for their combat veteran. One of the seven participants was disqualified from the interview process because she stated in her interview that she was not, yet a full-time caregiver and her spouse had no combat-related injuries.

Each participant was identified by their interview position followed by a pseudonym. Individual participants were randomly assigned a pseudonym of common cultural names by the research. Given the potential vulnerability of participants, I generally disguised or removed information that might directly or indirectly lead to the

identification of the participants and any other people, organizations, and places described. De-identifying data is fundamental when conducting studies on sensitive topics with small populations.

Molly, Danielle, Shannon, and Kelly were interviewed via Zoom, and Rev.com transcribed the audio. Due to scheduling and caregiving conflicts, Participants 5 and 6 chose to answer the questions via email, and member checking was done via Zoom in a subsequent interview. Although participants Lisa and Madelyn were interviewed via email, they generated rich qualitative data. At the end of each interview, Molly, Shannon, and Danielle were emailed a \$20 e-gift card. Participants Kelly, Lisa, and Madelyn declined the e-gift card as they were more interested in how their experiences could improve federal, state, and local resources and research for post-9/11 injured combat veterans.

## **Semi-Structured Interviews**

Participants filled out a demographic questionnaire and returned it to the interviewer. At the beginning of the interview, the interviewer introduced herself and the purpose of the study, followed by informing the participants of the minimal risks of their participation, such as emotional and psychological discomfort. After receiving their verbal consent, the interview began. The interview began with two icebreaker questions. The first question asked them to describe their favorite memory while dating, engaged, or married; the second asked them to describe their life before becoming a military spouse. The following questions asked about their life during deployment, reintegration, and transitioning to primary caregivers. The last two questions were forward-thinking, which

asked what policies and practices would be helpful for implementation at the VA and what they foresee in the next five years regarding their spouse and treatments/progress.

I spoke less and allowed for silence to allow the participants a moment to gather their thoughts. By allowing the silence, participants were more open and spoke more.

Thus, each face-to-face or audio recording was at least an hour long.

#### **Variations in Data Collection**

In the early stages of the data collection, I was confident I would secure 10-12 participants to reach data saturation. The initial plan was to recruit potential participants by posting recruitment flyers at veteran treatment and rehabilitation centers and Facebook groups. However, during the IRB approval process, I was told that VA and non-VA medical facilities have their IRBs that would need approval for posting flyers at their locations, which would be an extensive, time-consuming process. Thus, I recruited via Facebook, social media, and snowball sampling. I began recruiting through FB military groups. Joining Facebook military group pages required the approval of the group's administrator. I joined several groups and sent private/direct messages to the administrators. Some either did not respond to my request to post the research announcement flyer (see Appendix C) or blatantly responded, "No research allowed." Furthermore, much of the participation in the FB military groups diminished as people were more focused on the new standard created by the COVID-19 pandemic. With little progress on recruiting on FB military group pages, I started my military group page hoping to successfully recruit spousal caregivers of post-9/11 injured veterans. Most of the visitors to my page stated they were interested in the study but were not spousal

caregivers of post-9/11 wounded, injured, and sick veterans. However, they shared my page with their family and friends, and I garnered a few responses from spousal caregivers interested in participating in the study.

One variation in data collection was the data transcription. Initially, I intended to transcribe the data verbatim. However, research indicated that transcription is a notoriously time-consuming and often tedious task that can take three to eight hours to transcribe, depending on typing speed (McMullin, 2021). Thus, given the size of the research undertaking and the sensitivity of the topic, outsourcing transcription was chosen to a professional transcription service, Rev.com.

Another variation in data collection was the recruitment flyer. The compensation on the Research Announcement Flyer stated that participants would be given a \$25 Walmart or Target e-gift card for participation. However, a \$25 e-gift card could induce prospective participants with limited resources to act against their best interests. Thus, during the interview, participants were told they would be given a \$20 Walmart e-gift card after the study.

# **Data Analysis**

Colaizzi's strategy ensured the credibility and reliability of this qualitative study, which comprised a seven-step process. The first step in Colaizzi's (1978) seven-step process was transcribing all the subjects' descriptions or transcripts. There was a total of four participants who participated in the audio or video process; two participants returned the questionnaire. Each transcript was read and re-read to understand the content.

Thoughts, feelings, and ideas generated from subsequent readthrough, and previous

compassion fatigue studies served as a bracketing diary and were marked in the margins of the transcripts.

In the second step, I extracted significant statements such as emotions, behaviors, values, morals, and frustrations. I numbered them into a list that described the lived experience of spouses transitioning to primary caregivers for their injured post-9/11 combat veteran. There were 263 significant statements. The table below represents the significant statements pivotal to the study's findings.

In step three, I identified meanings relevant to the phenomenon that arose from carefully considering the significant statements. Colaizzi (1978) proclaimed that if the researcher approaches this step from the perspective of formulated meanings with the data rather than inserting meaning into the data, the researcher could minimize the risk of imposing personal perspectives related to preexisting knowledge, expectations, or experiences into the findings.

The fourth step was to arrange meanings, or codes, into categories to help themes emerge. In step five, the emergent, themes, the formulated meanings, and the significant statements merged to develop an exhaustive statement of the phenomenon. In step six, the researcher summarizes the exhaustive descriptive so there is an identification of the fundamental structure of the phenomenon. In the final step, the study participants validated the findings to compare to my descriptive results with the participants' experiences.

#### **Evidence of Trustworthiness**

# Credibility

Credibility refers to the degree to which the research represents the actual meanings of the research participants (Lincoln & Guba 1985). The confirmability of the results is influenced by reducing or, at a minimum, explaining any researcher's influence on the result by applying and meeting standards of rigor such as member checking, triangulation, and peer review (Johnson et al., 2019). Member checking tests the findings and interpretations with the participants (Lincoln & Guba, 1985). Lisa and Madelyn completed the interview via email and were member-checked via Zoom for accuracy. Final transcripts were returned to respondents to correct errors and assess data adequacy to no avail.

# **Transferability**

Transferability is the extent to which findings can be transferred to other settings in similar contexts (Lincoln & Guba, 1985). As the researcher, I provided a thick description of the participants and the research process to enable the reader to assess whether the findings were transferable to their setting. I also provided a rich account of descriptive data, such as the setting, sample, sample size, sample strategy, demographic, inclusion and exclusion criteria, interview procedure and topics, changes in interview questions based on the iterative research process, and excerpts from the interview guide.

## **Dependability**

Dependability is the extent to which the research would produce similar or consistent findings if replicated by another researcher is dependability (Lincoln & Guba,

1985). Dependability was established through an audit trail, which detailed the analytical steps in moving from raw data to final interpretation and demonstrated that the analysis follows a logical path based on the collected data.

## **Confirmability**

Confirmability, the last dimension of the criteria of trustworthiness, is a degree of neutrality or the extent to which the respondents shape the findings of a study and not researcher bias, motivation, or interest (Lincoln & Guba, 1985). Confirmability was also established through reflexivity as I actively engaged in critical self-reflection about the potential biases and predispositions they bring to the qualitative study. With reflexivity, I became more self-aware, monitored, and attempted to control and do my best to be always on guard of my biases, preconceptions, and assumptions that I might bring to this study.

#### **Results**

I sought to understand the lived experiences of spouses who transitioned to primary caregivers for their injured post-9/11 combat veteran and their susceptibility to compassion fatigue. Interviewees were asked nine sub-questions to answer the primary research question. Participants all identified themselves as spousal caregivers. Three themes emerged after reading the transcripts, watching the video interviews, and data analysis. These three themes were instrumental in advancing public and social policy to promote spousal caregivers' mental health and well-being, delineating effective caregiving practices, building public awareness of caregiving needs, and enhancing caring communities.

## **Presentation of Themes**

Three major themes emerged from the semi-structured interviews with spouses that transitioned to primary caregivers for their post-9/11 combat veterans. The first central theme was isolation, with the subthemes of isolation and emotional distress. The second theme was emotion management. The third theme was radical acceptance, with subthemes of seeing emotions differently and self-efficacy. Radical acceptance is acknowledging and tolerating the present situation without judging yourself or others or trying to change it. Most caregivers expressed their powerlessness in changing or improving their situation with their spouse because their life changes daily.

The following themes, followed by direct participant quotes, are listed below. The direct quotes give credibility to the study and help answer the main research question and sub-questions, which describe the lived experiences of spouses who transition to primary caregivers for their post-9/11 injured combat veteran.

## Theme 1: Isolation

While participants described loneliness during the early part of their marriage during their spouse's deployment and, in some cases, over multiple deployments, most participants identified with isolation when they transitioned to the primary caregiver for their injured spouse. Spousal caregivers acknowledged they could not form meaningful social connections with others and lacked a sense of belonging.

Participants felt isolated because they had to abandon their previous habits, routines, and lifestyles to adapt to their caregiving responsibilities. Furthermore, many of these spousal caregivers felt isolated as their family and friends were oblivious to their

situation and offered little support. Additionally, COVID-19 forced these caregivers to stay at home and quarantine in concert with their caregiving duties, contributing to a freezing cauldron of social isolation, sheer boredom, and a penetrating feeling of loneliness. In her interview, Molly described how her life centers on her husband's care, which has altered her life:

I used to have friends. I used to have family. I wanted to get into, before him, I wanted to get into marketing and advertisement and whatnot. Now I want to get into mental health and changing the way mental health is looked at because we're not just numbers. We're people. Yes, trying to change the perspective of my husband has challenges, he's not his own challenge.

People not understanding her husband, or his needs kept Shannon isolated. She noted: "His family is completely oblivious to it, which is a pet peeve of mine. He's had panic attacks in front of him, and nothing. So, that's frustrating." Danielle did not discuss isolation as part of her emotion; however, she was inferred feelings of isolation when her husband was on deployment a year after the birth of their first child: "Well, I mean, I didn't really have to have any support with that because I was a stay-at-home mom, so yeah."

Although Kelly had a strong support system, people not understanding her role as a military spousal caregiver, keeps her isolated from the outside world:

Yeah, yeah. I don't think anybody truly understands the hell of our spouses transitioning from the military. My god, it is horrible. Especially, when there's not those supports there. Yeah. It is pretty bad. It's hard to even put into words

sometimes. There definitely needs to be more studies about that, too, because I felt like I had nowhere to go, and I was dealing with it by myself. It was a lot, for sure.

Lisa was in a dual-military marriage with a two-month-old son when her husband deployed:

During our first deployment married-we had a two-month-old son. As a young couple, we never were able to establish any strong communication skills, so our relationship felt strained during the deployment. I was an Active-Duty Soldier, acting as a single parent, working close to sixty hours a week, and a deployed husband-I would say I was stressed.

#### Loneliness

These caregivers talked about how the absence of a support system or outside caregiver support groups has increased their feelings of loneliness. Caregivers also stated that their civilian friends were unrelatable and could not express their frustrations and burdens associated with caregiving; thus, they had no "listening ear." Caregivers were also lonely because they had no respite help. Caregivers also stated that their loneliness increased during COVID-19 because they lost their social connectivity to other VA caregivers and veteran groups.

Shannon stated, "I have to manage the stressors and I have to manage the days that he's depressed for no reason...and then you add COVID on top of it and just let's shut down, literally, let's shut down all the mental health resources."

#### **Emotional Distress**

Many caregivers expressed emotional distress due to their need to discontinue their educational and professional development to care for their post-9/11 injured combat veteran.

# Theme 2: Emotion Management

When spouses started their caregiving journey, they had to check their emotions.

Not putting on a brave face could compromise their ability to care for their spouse.

Some participants experienced extreme emotions that needed managing when transitioning to the primary caregiver. Spousal caregivers stated that they demonstrated one emotion on the outside while feeling very different on the inside.

Shannon's Response:

So, I remember at some point in therapy, when we were doing therapy really intensely, both of us. Because that's what PTSD looked like, I thought our marriage was ending. I remember I looked at him and I was like, "I have to get to know a new person. You are not the man I married." So, we're on year number two of trying to figure out who he is now.

Danielle stated that she was unaware of what caregiving was and that she would become her husband's caregiver:

So even along the whole way with the whole entire thing, I've been kind of humble and calm as far as people see on the outside, but that's not so on the inside, you know? So, it's been a job. It's been a surprise. It's been a rollercoaster,

but through it all, so you stay strong for yourself, your husband, and your kids, and for the outside world.

Kelly managed her emotions because her adult sons play a major role in helping her with her husband:

Right now, it's honestly a lot easier because three of my kids are adults. They can help out if I need them to, whether it's taking their sister to an appointment, pick up their niece, take my husband, do something that just my husband can't because of his injuries or that I can't just because I'm too short. My boys are 6'6".

# Cognitive Reappraisal

One pervasive strategy a spousal caregiver may use to regulate their emotions is cognitive reappraisal. Cognitive reappraisal involves changing how one thinks about a situation to change its emotional impact (Gross, 2002). For example, caregivers reappraised their negative feelings of transitioning from primary caregivers to reaffirming their love and bonding with their spouse. However, cognitive reappraisal is private and intrapsychic. It causes many of these spousal caregivers to alter the trajectory of their emotional responses because they reinterpret the meaning of a situation (Wolf et al., 2016).

# **Emotion Reframing**

Through emotion reframing, caregivers reframed a socially inappropriate emotional expression by publicly attributing it to an appropriate source to shape observers' perceptions (Wolf et al., 2016). Through emotion reframing, spousal caregivers believe that unconditional positive regard is always maintained, working with

what is, and not what should be (Brooks, 2016). More specifically, caregivers started living in the reality of the limitations of their spouse, and their caregiving duties would commence sooner than later. Through emotion reframing, caregivers could actively assist their spouses with their thoughts and feelings, helping them to rely less upon false assumptions they hold onto about themselves, other people, their options, and their resources (Brooks, 2016).

# Theme 3: Radical Acceptance

Radical acceptance teaches that although an individual would not choose to have a situation, resisting or fighting situations that cannot be changed exacerbates emotional suffering and intensifies the pain of being in that situation (Burton et al., 2020). Moreover, radical acceptance teaches that acceptance does not mean giving up, agreeing with the situation, or pretending to be happy (Burton et al., 2020). Instead, acceptance at the moment ultimately allows for a greater focus on adaptive coping, emphasizing acceptance rather than immediate problem-solving (Lois & Miller, 2018).

Radical acceptance is a practice that helps a person evaluate situations and work to reduce the emotional burden of the reality of the situation, like resentment, anger, hatred, or shame. Participants stated to care for their spouse's well-being properly, they had to accept their new role as caregiver and the limitations of their spouse. Participants accepted their new roles without hesitation.

Shannon took solace in knowing her caregiving role was not as challenging as others:

But I remember realizing that it was going to be a lifetime. That this was never going to go away, and that this was probably only going to get worse over time.

And it was just kind of accepting it and moving on, because you just take the new normal, and you do the best you can with it.

Danielle accepted her caregiving role as being given by God:

So, you just be okay. You just have to make yourself be, oh, just tell yourself.

Well, it's okay. But yeah. And so I just take it and go with it because the kind of person that I am, kind of mindset, strong will and all that good stuff. Thank God.

God picked the right one to give it to, I'll tell you that much.

Kelly recognized that she would have to take care of her husband the rest of his life as his injuries worsen over time:

Honestly, I was terrified, because not knowing how fast the TBI is going to progress. The other things we could deal with, because body aches and pains, chronic pain, injuries like that, they heal much better than a TBI. The TBI, unfortunately, it doesn't get better with time. It just tends to get worse. I'm looking at it like, "Okay, he's younger than me. He's going to outlive me, and now I have to take care of him-And it's possible I'm going to have to take care of him like I'm his mother, because we don't know how it's going to be in the future. He may be in complete dementia or Alzheimer's at some point." We don't know, so I was pretty freaked out.

Lisa acknowledged her husband would live with chronic pain:

When you live with chronic pain, all you think about are the "what-ifs" and that you're not good enough anymore. The pain alters your mind, and it takes over if you're not willing or strong enough. Through a 180-degree life change, my spouse and I strengthened our minds, and it helped us deal with the pain.

Madelyne was able to accept her husband needed a caregiver because of her faith:

Our life has changed because of his condition, and I had questions as to why this happened to us. But my faith in the Lord helped me to accept our fate. It could have been worse, so I was thankful that in spite of his condition, the mere fact that he's with us, is more than enough consolation.

When the concept compassion fatigue was introduced to participants, they said they had never heard of it but found it relatable. They focused on the exhaustion and stress from caregiving. Next, spousal caregivers expressed frustration and exhaustion from caregiving. Thus, even with the complexities of spousal caregiving, placing their spouse in a long-term residential/assisted living facility or respite care was never an option. Even though most facilities have the time, skill, and capability to care for an injured combat veteran, spousal caregivers believed they would remain their caregivers because they did not believe anyone could care for them as well as they could.

Spousal caregivers did not believe their spouse would improve or adjust sufficiently to any other caregiver. Third, spouses with younger or teenage children were dual parents in concert with caregivers and spouses. Many spousal caregivers stated that the extent of their spouse's injury/injuries kept them from being hands-on with the

child(ren). Fourth, spouses agreed that the injuries changed their spouse more than physically.

Many former post-9/11 combat veterans were outgoing and social, but the injuries and immeasurable pain caused personality changes, mood changes, and sometimes, pessimism. Lastly, spousal caregivers were confident that within the next five years, the VA would introduce policies and programs to address invisible injuries of post-9/11 combat veterans. Some spousal caregivers were equally confident that their spouse could regain some (lost) functionality with the advancement of technology and medicine.

## Seeing Emotions Differently

Spousal caregivers started seeing their feelings and experiences more positively than negatively. While many caregivers were unprepared for their caregiving role, they understood it was an extension of their marital vows. Caregivers also stated they had to become proactive in their spouse's care with their doctor and care team, such as being more vocal, doing more research, and being more vocal about their spouse's care, pain, and appointments. By seeing emotions differently, caregivers could accept their spouses in their present reality rather than who they were pre-injury.

# Self-Efficacy

Self-efficacy is a construct that refers to an individual's belief in performing confidently and capably in specific situations (Tan et al., 2021). Conceivably, caregivers who possess a higher sense of efficacy are more likely to frame caregiving tasks as challenges, are better able to recover from setbacks, and are more likely to persist in

finding ways to cope (Tan et al., 2021). On the contrary, caregivers with lower self-efficacy are more prone to ruminating on the consequences of failures and their deficiencies (Tan et al., 2021). However, caregivers with positive self-efficacy were also involved in caregiver support groups, which positively affected the caregiver's coping ability, knowledge, and social support (Tan et al., 2021). Much of the caregiver's self-efficacy was rooted in their positive outlook on life and the recommendations of possible interventions for their spouses.

## **Summary**

In this chapter, I discussed the setting, demographics, data collection, data analysis, and evidence of trustworthiness. Results of interviews were analyzed. Three themes emerged: isolation, emotion management, and radical acceptance. Most of participants felt isolated during their spouses' deployment. Isolation intensified when spouses became caregivers and had little to no familial support. Emotion management refers to how spouses regulated their emotions to adapt to caregiving. Spousal caregivers had to manage their emotions to have the ability to care for their injured spouses. Radical acceptance involves coming to terms with spouses after deployment from post-9/11 wars. Participants had to radically accept and acknowledge their spouses' limitations as well as daily and long-term needs. Significant findings, conclusions, and implications for future research are identified in Chapter 5.

# Chapter 5: Discussion, Conclusions, and Recommendations

### Introduction

The purpose of this transcendental phenomenological study was to examine lived experiences of Army spouses who transitioned to primary caregivers for post-9/11 Army combat veterans and their susceptibility to compassion fatigue. When post-9/11 Army combat veterans have military service-connected disabilities, they often require long-term care due to disabling physical, emotional, or cognitive conditions. Often, their spouses become primary caregivers. While spousal caregivers are a vital source of informal care for their spouses, they often are at risk for compassion fatigue.

This study was guided by the research question: How do military spouses describe their experiences with transitioning to the primary caregiver role for post-9/11 veterans? Figley's compassion fatigue theory guided this study. This chapter includes an overview of interpretations of findings, study limitations, recommendations, and implications. The chapter concludes with an overall summary.

### **Interpretation of Findings**

The goal of this study was to explore Army spouses and their lived experiences involved with transitioning to primary caregivers for post-9/11 combat veterans. A qualitative design was most appropriate for this study to focus on events that transpired and outcomes of those events from the perspectives of those involved. Through semi-structured interviews, six participants revealed three themes, with two subthemes for each theme. The first theme was isolation, with the corresponding subthemes loneliness and

emotional distress. The second theme was emotion management, with cognitive reappraisal and emotion reframing as subthemes. The last theme was radical acceptance with subthemes of seeing emotions differently and self-efficacy.

#### Theme 1: Social Isolation

Social isolation is an objective and quantifiable lack of or reduction of social network size and social contact (Grycuk et al., 2022). Social isolation is a decisive risk factor for compassion fatigue among spousal caregivers. Spousal caregivers of post-9/11 combat veterans are less likely to be physically active than caregivers or non-caregivers with more robust social bonds (Singh et al., 2021). In addition, social isolation and loneliness may lead to chronic stress, contributing to compassion fatigue (Singh et al., 2021).

Spousal caregivers experience life changes that interfere with their routines while being caregivers (Thana et al., 2021). Involvement in caregiving tasks requires adjustments to caregiver daily routines and disruption of social activities (Bayen et al., 2017). Intensity and demands of caregiving and limited time for outside social activities may cause spousal caregivers to feel socially isolated (Thana et al., 2021).

Participants stated increased responsibilities due to caregiving for post-9/11 combat veterans limited time for social activities, contributing mainly to feelings of social isolation. Furthermore, participants stated that they isolated themselves from family, friends, and colleagues and felt they were a burden to them. Spousal caregivers also lost their established social networks with other informal caregivers in support groups during the pandemic. While the term social isolation is typically used

interchangeably with loneliness, they are two distinct concepts. Loneliness and emotional distress are discussed in the next section.

### Subtheme 1: Loneliness

The first subtheme of social isolation is loneliness. Loneliness occurs when an individual perceives a mismatch between their desired and achieved level of social interaction (Fee et al., 2021). Loneliness is a subjective and personal feeling. Participants described their loneliness because of caregiving.

# Subtheme 2: Emotional Distress

The second subtheme of social isolation is emotional distress. Emotional distress is a state of suffering associated with daily stressors and challenging demands (Arvidsdotter et al., 2015). Participants in this study admitted they experienced high degrees of emotional distress. Spouses are the primary source of emotional support for post-9/11 combat veterans, as they tend to be the primary providers of both practical and emotional care (Limonero et al., 2020).

## **Theme 2: Emotion Management**

Spouses should be empathetic, but at the same time, detachment is an emotion management strategy (Martínez-Morato et al., 2021). However, emotion management involves stress (Martínez-Morato et al., 2021). Many spousal caregivers may manipulate their emotional boundaries to function as a filter through which they interact with their spouses to be physically and cognitively present while controlling their emotional connections and performing in social situations to avoid embarrassment (Carminati et al., 2021).

## Subtheme 1: Cognitive Reappraisal

Cognitive reappraisal is a strategy that is used to regulate emotions. This strategy involves deliberately reframing an ongoing event or memory by reinterpreting the experience, focusing on a positive outcome, or finding a silver lining (Samide & Ritchey, 2020). Cognitive reappraisal involves changing how one thinks about a situation in order to change its emotional impact (Gross, 2002). Spousal caregivers cognitively reappraise negative emotions as positive (Crum et al., 2013). Cognitive reappraisal involves implementing interpersonal behaviors that are appropriately focused on social interactions that are perceived by others as emotionally engaging and responsive (Cutuli, 2014).

# Subtheme 2: Emotion Reframing

Emotion reframing involves a shift from one appraisal of emotion to another (Wolf et al., 2016). Through emotion reframing, spousal caregivers focus on the greater purpose as accomplished through caregiving (Deery et al., 2019). Although caregiving is stressful, spousal caregivers view caregiving tasks as challenging and rewarding, giving caregiving meaning (Baum, 2020). Spousal caregivers reframe their caregiving by focusing on meaningful and satisfying bonds with their spouses (Polachek & Wallace, 2018). Participants described transforming their negative emotions to more positive ones by expanding alternative meanings of emotion-eliciting events and cultivating a sense of personal agency.

## Theme 3: Radical Acceptance

Through radical acceptance, spousal caregivers learned to embrace discomfort, change, and painful emotions (Werner, 2020). Spousal caregivers do not tell themselves that caregiving is okay or even that they enjoy it, but they acknowledge that caregiving is their current reality and deserves to be accepted (Werner, 2020). The participants reported that during the acute rehabilitation phase, they had to understand what happened, manage their expectations for recovery, and start coming to terms with the situation (Zanini et al., 2021). By radically accepting that they are now the primary caregivers for their post-9/11 combat veteran, spousal caregivers learned to handle stressful situations by getting past the moment. For example, spousal caregivers could no longer think of their spouses before their injury; they learned to let go of what was and accept their spouses for what they are in their current state. More importantly, rather than embracing caregiving, radical acceptance permits one to acknowledge when something is too much to process at any moment (Ruiz, 2021).

## Subtheme 1: Seeing Emotions Differently

Emotions act more like a wave, at times increasing and becoming more intense, but inevitably always reaching some plateau, subsiding, and finally passing (Centre for Clinical Interventions, n.d.). Spousal caregivers acknowledged they had emotions that moved and changed while caregiving for their post-9/11 combat veteran; however, they understand the emotions were not permanent (Centre for Clinical Interventions, n.d.). By seeing their emotions differently, spousal caregivers could tolerate the negative feelings associated with caregiving. The spouses valued their commitments to the family's well-

being and strongly believed in destiny (Huang et al., 2019). These qualities allowed them to accept their situation and gave them the willpower to overcome difficult situations related to spousal caregiving (Huang et al., 2019).

## Subtheme 2: Self-Efficacy

Self-efficacy is essential in understanding the informal caregiver's perceived ability to execute caregiving tasks (Hall, 2014). Self-efficacy means confidence in acting appropriately to attain the expected results in potentially stressful situations (Pérez-Fuentes et al., 2020). Caregiving self-efficacy is related to reduced burden and anxiety and increased positive aspects of caregiving and self-care behaviors among caregivers (Leung et al., 2020). Caregivers with high levels of self-efficacy are proactive in self-care and completing activities that help improve health. In contrast, caregivers with low self-efficacy are likely to experience adverse outcomes such as anxiety and depression (Leung et al., 2020). Spousal caregivers in this study reported self-efficacy in navigating the caregiving experience.

The themes revealed by the six study participants confirm that these spousal caregivers are at risk for compassion fatigue. Spousal caregivers were often stressed and exhausted from caregiving. Social isolation, including loneliness and emotional distress, may contribute to the development of compassion fatigue.

#### Limitations

Several limitations in this study merit discussion. The first limitation was that the research was a phenomenological design because it resulted in smaller sample sizes, which inevitably raised questions about the representativeness and transferability of

findings. The small sample size could be attributed to the slowness of negotiating access to social networks and the social climate due to the COVID-19 pandemic. Another drawback to phenomenology is its proneness to researcher subjectivity, complex data analysis, and the limited scope in generalizability. Although I was transparent and reflexive about the data collection processes, analysis, and presentation, the findings could be rooted in researcher bias. The second limitation of this research was that the data was from one group of spousal caregivers of post-9/11 combat veterans from the Army, which makes it impossible to generalize to other spousal caregivers of post-9/11 combat veterans from other branches of the U.S. Armed Forces, which may have limited the scope, richness, and usefulness of the study data. The homogeneity of the participants is another weakness. The data used for this project were solely from female spousal caregivers of post-9/11 combat veterans. Male spousal caregiver participants may have yielded different results. Lastly, a potential bias could be that compassion fatigue reported by spousal caregivers may not be attributed to the caregiving experience, but may reflect other underlying issues, such as other things experienced by caregivers.

#### **Recommendations**

Due to the cost of caring for the wounded, injured/ill, and sick post-9/11 veterans and the number of services spousal caregivers provide, it is imperative to identify ways to support caregivers and reduce their susceptibility to compassion fatigue (Watford et al., 2019). The study revealed that the lived experiences of spousal caregivers of post-9/11 combat veterans are very well susceptible to compassion fatigue.

Based on the responses from the spousal caregivers in this phenomenological study and suggestions from other studies, recommendations for spousal caregivers, medical personnel, social services, policymakers, and future research are outlined below.

## **Spousal Caregivers**

Studies reveal three critical recommendations for reducing the harmful effects of compassion fatigue. First, spousal caregivers should seek professional intervention when the level of distress reaches an unsustainable level of severity where professional help may be desirable or even necessary (Teater & Ludgate, 2014). Next, caregivers must be recognized in healthcare settings (California Task Force on Family Caregiving, 2018). Although spousal caregivers may not immediately identify as caregivers, they frequent healthcare settings where the term is applied to them (California Task Force on Family Caregiving, 2018). Suppose spousal caregivers begin to recognize themselves as caregivers at hospitals and primary care offices. In that case, they will be better equipped to add their voices to a caregiver constituency/movement (California Task Force on Family Caregiving, 2018).

Next, given the high degree of support from social networks, spousal caregivers must identify individuals they could contact for emotional/caregiver support (Lee et al., 2022). Having identified individuals in mind early on may encourage spousal caregivers to reach out for support earlier (Lee et al., 2022). Such an approach would also address the challenge of role conflict because research suggested discussions of role conflict with family and other close contacts would help (Lee et al., 2022). The development and

implementation of caregiver support checklists that include topics for discussion may be helpful (Lee et al., 2022).

### **Medical Personnel**

Healthcare providers are essential in helping the spouse transition to the primary caregiver for their post-9/11 combat veteran. First, healthcare provider knowledge and awareness of the extent of role change for caregivers and recipients and the associated emotions are essential. For example, spouses assume the role of financial decision-maker for the first time, providing personal care and attempting to manage aggression. These changes evoke emotions ranging from grief to empowerment (Macdonald et al., 2020). Next, healthcare providers and spousal/partner caregivers need to have access to up-todate knowledge and tools on all information and resources relevant to spousal caregiving of post-9/11 combat veterans, including caregiver assessments (information about veteran injury, injury management, how to access professional resources to assist with care, knowing when to ask for help) (Macdonald et al., 2020). Support for spousal/partner caregivers is of high importance, that is, support in the form of education on combat veteran injury management from healthcare providers, provision of personal care to the person with combat injury who is resisting, respite to allow the caregiver personal time to undertake household duties, and social support to keep the caregiver connected to the community because time away from home diminishes as care recipient needs increase over time (Macdonald et al., 2020). Lastly, the healthcare system must improve the lack of information about healthcare system processes, including staff roles, staff transitions,

and discharge plans, and address concerns about patients receiving poor care (Blok et al., 2023).

Additionally, healthcare providers, including registered nurses and physicians, could become essential sources of social support for spousal caregivers (Jiang et al., 2022). Healthcare providers should realize that their support could strengthen spousal caregivers' resilience to face the spousal caregiver, help caregivers view the caregiving role positively or neutrally, and reduce their susceptibility to compassion fatigue (Jiang et al., 2022). Healthcare providers could offer illness-related knowledge, policies on financial support, and coping skills to support spousal caregivers for better management of patient's symptoms (Jiang et al., 2022).

#### **Social Services**

Social service workers should follow the national strategy for caregivers and supportive caregiving policies of the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act to ensure that spousal caregivers have the emotional and mental support they require. This legislation suggests developing a coherent and coordinated plan for policy initiatives, data infrastructure, and supportive programs to better address caregiving families' needs (Aufill et al., 2019). Fundamental to the success of such a national plan will be the integration of evidence-based services and support across healthcare organizations, social service agencies, and employers (Aufill et al., 2019). However, more than a stand-alone national plan is needed; the national strategy developed under the RAISE Family Caregivers Act must accommodate, extend, and reinforce the efforts of states and local communities (Aufill et al., 2019).

Another recommendation is for social service workers to provide spousal caregivers with information about services like adult day care. Adult daycare provides health oversight, socialization, and therapeutic activities in a supportive group environment (Aging Services Council of Central Texas, 2018). This community resource not only allows post-9/11 veterans with physical or cognitive impairment to receive necessary care while continuing to live at home but also gives their caregivers time away from the demands of caregivers (Aging Services Council of Central Texas, 2018).

# **Policymakers**

Data must clearly define a policy problem. Even if spousal caregivers are unlikely to identify aspects of this role as policy problems, data can shape a problem meriting a policy response (California Task Force on Family Caregiving, 2018). Current data sources on spousal caregivers of post-9/11 combat veterans have many areas for improvement. Addressing these weaknesses so there is high-quality data on caregiving populations will facilitate more precise problem definition (California Task Force on Family Caregiving, 2018).

Policymakers should establish an ongoing process to proactively share information and best practices with states about programs it administers that are available to serve caregivers, especially in states with a relatively large share of spousal caregivers of post-9/11 combat veterans (United States Government Accountability Office [USGOA], 2020). Policymakers should leverage regional office staff to provide additional assistance and information sharing, particularly related to spousal caregiver navigator programs (USGOA, 2020). The second recommendation is for policymakers to

provide targeted interventions to reduce compassion fatigue amongst spousal caregivers of post-9/11 combat veterans (Bom et al., 2019). Policymakers must invest in support for spousal caregivers by offering relief from caregiving tasks or by organizing support groups that might reduce the negative consequences of spousal caregiving, specifically compassion fatigue (Bom et al., 2019). As the strength and presence of the caregiving effect strongly differ between subgroups of caregivers, policymakers should aim to target subgroups of spousal caregivers of post-9/11 combat veterans who experience the most significant impact of compassion fatigue (Bom et al., 2019).

### **Future Research**

There are gaps in our current knowledge about the severity of spousal caregiving and the spouses' vulnerability to compassion fatigue. More longitudinal studies are needed to identify how spousal caregiving can make spouses susceptible to compassion fatigue. Further studies are needed to determine the susceptibility of compassion fatigue among spousal caregivers from the perspective of the care recipient (Liu et al., 2020). However, it is essential to acknowledge that this kind of research will hinge upon successfully recruiting spousal caregivers from underrepresented populations, which will require building strong community partnerships (Lwi et al., 2022). Greater community engagement can be facilitated by having culturally representative and competent researchers involved in participant recruitment and administering research procedures (Lwi et al., 2022). Such community engagement can increase the likelihood that in-depth, well-powered, and ecologically valid research will determine how compassion fatigue can impair the caregiving of the post-9/11 combat veteran (Lwi et al., 2022). Importantly,

community engagement can also provide additional opportunities for psychoeducation, a necessity for helping people recognize symptoms of compassion fatigue among spousal caregivers and increasing willingness to seek out needed support and professional services in caregiving communities (Lwi et al., 2022).

Engaging in community outreach and overcoming common recruitment challenges (e.g., stigma, retention, trust) is critical for including greater diversity in the dementia caregiving literature and increasing cultural competence in health care (Lwi et al., 2022). The relationship between the spousal caregiver and the spousal care recipient must be examined (Hajek et al., 2021). Due to the low coverage and accessibility of psychological support options, researchers should develop innovative support measures, such as online support groups or psychological support interventions (Biliunaite et al., 2022). Lastly, tailored interventions are needed to reduce the effects of compassion fatigue among spousal caregivers. Future studies must investigate compassion fatigue among spousal caregivers in other sociocultural contexts and their implications on health and well-being (Sung et al., 2022).

# **Implications**

This study affirms that spousal caregivers represent a valid, unique, and heterogeneous group of caregivers and that recognition of this construct is essential for sound policy and practice (National Joint Committee on Learning Disabilities, 2023).

Current research and reasoned principles should guide policies (National Joint Committee on Learning Disabilities, 2023) concerning spousal caregivers of post-9/11 combat veterans. Policies must ensure that spousal caregivers of post-9/11 combat veterans have

access to expert instruction, appropriate related services, and caregiving education specific to combat veterans (National Joint Committee on Learning Disabilities, 2023). The following subsections will outline implications for policy, implications for positive social change, theoretical implications, and empirical implications.

# **Implications for Policy**

This study revealed several policy implications for spousal caregivers of post-9/11 combat veterans. This study found that many spousal caregivers experienced adverse physical and psychological health and were susceptible to compassion fatigue from caregiving. Policy implications that the federal and state governments can implement are listed below.

The first policy implication is for federal and state governments to acknowledge the threat of compassion fatigue beyond healthcare workers. The onset of the COVID-19 pandemic prompted many researchers to understand burnout, exhaustion, and anxiety among nurses, doctors, and other healthcare workers (van Roekel et al., 2020). Thus, these healthcare workers were at heightened risk of compassion fatigue and burnout, which was associated with more medical mistakes, accidents on the job, lower compliance with regulations, and client satisfaction, as well as lower in-role and extrarole performance (Sciepura & Linos, 2022). These findings could apply to spousal caregivers. However, compassion fatigue in concert with burnout is two measures of psychological distress rather than separate constructs. The government must promote open conversations about compassion fatigue, helping to decrease the internalized stigma of spousal caregivers of post-9/11 combat veterans seeking mental health support (Hasan,

2021). By actively educating spousal caregivers about risks, mitigating factors, and self-care strategies, compassion fatigue can be understood and potentially averted (Salmond et al., 2019).

The second policy implication is for the federal and state governments to promulgate a policy that supports establishing systems and managerial support for managing critical incidents, providing needed respites, and ongoing education (Salmond et al., 2019). Studies on respite care have shown that caregivers who used respite care had decreases in self-reported caregiver burden over time compared to caregivers who did not (Florida Policy Exchange Center on Aging, 2021). While no studies on respite care have addressed compassion fatigue directly, respite care could reduce spousal caregivers' vulnerability to compassion fatigue. By advancing a policy to provide funding to spousal caregivers of post-9/11 combat veterans, spousal caregivers will have improvements in overall well-being, be able to sustain their caregiving roles, and provide a better quality of care to the combat veterans (Florida Policy Exchange Center on Aging, 2021). An additional intervention toward a successful intervention and resolution of compassion fatigue is education (Saleh et al., 2021). Many spousal caregivers lack adequate information about providing the best care for their post-9/11 combat veteran and must learn trial-and-error techniques to keep their spouse safe (Fife et al., 2020). Furthermore, many caregivers must learn how to navigate government support or healthcare systems (Fife et al., 2020). Educational programs may include enhancing overall communication strengths, improving team collaboration and relationship skills, adding stress management, conflict management, and emotional intelligence training, or other

programs that could enhance caregiver proficiency (Saleh et al., 2021) and reduce compassion fatigue.

Another policy implication for spousal caregivers for post-9/11 caregivers is to ensure adequate support for caregivers in dealing with compassion fatigue (Salmond et al., 2019). The findings in this research study may incite institutional changes in hospitals and rehabilitation centers that care for post-9/11 combat veterans, such as creating policies and guidelines toward developing preventive interventions or psychosocial support for spousal caregivers (Wu et al., 2016). For example, healthcare organizations must create preventive interventions and provide psychosocial counseling for spousal caregivers experiencing compassion fatigue (Saleh et al., 2021). Providing spiritual resources is another preventive intervention to mitigate compassion fatigue (Saleh et al., 2021). Community and religious programs can promote various spiritual practices, develop culturally responsive programs and training, and provide opportunities and support groups for spousal caregivers to participate in spiritual practices and reduce feelings of isolation (Fife et al., 2020). These programs can coordinate with religious and spiritual organizations to provide opportunities for caregivers in urban areas to participate in group meetings where they can participate in spiritual practices together, whether it be prayer, devotion reading, weekly church services, meditation, or walking in nature (Fife et al., 2020).

Efforts should also be made to provide adequate respite services so caregivers can participate in spiritual practices as they wish (Fife et al., 2020). Local veteran care centers and clinics can play a role by providing information about spirituality as a coping

mechanism in their caregiver educational and training materials, as well as a contact list of information for local spiritual and religious resources (e.g., church services, religious events, and activities, spiritual resources, traditional events, and activities) (Fife et al., 2020). In addition, religious and spiritual organizations should undertake efforts to provide respite opportunities for their caregiver members to participate, and the role of healthcare providers can be to encourage the use of spiritual practices to spousal caregivers of post-9/11 combat veterans when appropriate (Fife et al., 2020).

# **Implications for Positive Social Change**

Spousal caregivers are often seen as outside observers or simply as care providers (Junkins et al., 2020). Due to their marginalization, spousal caregivers remain vulnerable and invisible to the effects of compassion fatigue. This research illuminated the need for positive social change for spousal caregivers of post-9/11 combat veterans second-order patients who also need and deserve care (Teixeira et al., 2019). Positive social change is a deliberate process of creating and applying ideas, strategies, and actions to promote the worth, dignity, and development of individuals, communities, organizations, institutions, cultures, and societies (Walden University, 2023c).

### **Individuals**

A spousal caregiver is the primary caregiver for their post-9/11 combat veteran, providing emotional and practical support for participation in meaningful daily activities and accessing health care and support services (Han & Radel, 2016). As such, some spousal caregivers may not seek support services because they believe that caregiving is their role and responsibility (Han & Radel, 2016). Spousal caregivers of post-9/11

combat veterans may feel guilty for considering the use of a nonfamily service, believing that the service will result in adverse outcomes for their spouse, that the use of such services represents role failure, or that such services exist to provide respite to the caregiver (Han & Radel, 2016).

### **Communities**

Spousal caregivers' compassion fatigue is increased by the lack of health facilities, including access to healthcare services, physicians, telemedicine, counseling centers, and psychological support (Rahimi et al., 2021). Thus, it becomes necessary for community members to provide a comprehensive system of support for spousal caregivers (Rahimi et al., 2021). Communities should organize health education and mutual support groups to create opportunities for caregivers to communicate with others, increase their knowledge, and alleviate the psychological pressure of caregiving (Chen et al., 2019). Furthermore, communities have a social responsibility to create programs to support the spousal caregiver and the post-9/11 combat veteran and facilitate meaningful experiences that spouses can share that may help reduce compassion fatigue (Gallagher & Rickenback, 2019).

# **Organizations**

The DoVA, which focuses on military injuries and rehabilitation of post-9/11 combat veterans, and the non-profit agency, the Elizabeth Dole Foundation, which focuses on the well-being of informal caregivers of veterans, can bring compassion fatigue and its implications on spousal caregivers to the forefront. These two agencies' concerted efforts will be instrumental in providing care to the veterans and subsequent

care to the spousal caregivers. Also, the DoVA can help veterans with mental health concerns exacerbating their physical health. On the other hand, the Elizabeth Dole Foundation is an ideal advocate group to raise awareness of the daily issues that military caregivers confront, with particular emphasis on spousal caregivers of post-9/11 combat veterans and their susceptibility to compassion fatigue.

The participants in this study stated they needed to prepare for the transition to the primary caregiver for their post-9/11 combat veteran. Many spousal caregivers expressed that they did not realize the magnitude of becoming the financial provider and the caregiver (Huang et al., 2019). These spouses are on a harrowing journey of learning to 'become' a caregiver (Hooper & Collins, 2019). Spouses needed to alter their lifestyles to assume the additional responsibilities of being a caregiver; they struggled to balance their previous responsibilities with the changes resulting from the combat veteran's injuries (Huang et al., 2019). Some participants reported a lack of information, training, and guidance; the focus was always on the combat veteran, and there was a lack of support in preparing spousal caregivers for a "lifetime job" as a caregiver (Zanini et al., 2021). As such, the DoVA and the Elizabeth Dole Foundation could offer educational programs to increase caregivers' confidence and competence in providing safe and effective care, as could the services addressing compassion fatigue (Zanini et al., 2021). Similarly, the adequacy of services that support caregivers in dealing with challenges linked to housing, bureaucracy, financial issues, and balancing caregiving and personal life needs to be assessed (Zanini et al., 2021).

The DoVA and the Elizabeth Dole Foundation should work with clinicians to ensure that psychological and psychophysiological symptoms of spousal caregivers are screened as part of the routine care provided by healthcare professionals (Teixeira et al., 2019). Moreover, from a prevention point of view, psychosocial support should be provided to cancer caregivers in an early phase of the caregiving process to avoid the development of psychophysiological symptoms (Teixeira et al., 2019). Spousal caregivers of post-9/11 combat veterans should warrant even greater attention from health professionals (Teixeira et al., 2019). Interventions should be specific to the experiences of spouses who transition to full-time caregivers for their post-9/11 combat veteran, such as self-help groups or psycho-educational stress management groups for this specific cohort of veteran caregivers (Teixeira et al., 2019).

### **Institutions**

Public health entities must bring key stakeholders from multiple sectors and the spousal caregivers of post-9/11 combat veterans to develop a broad, 360-degree, macrolevel approach to promote caregiving (Centers for Disease Control and Prevention, [CDC], 2020). This process would identify community assets, uncover inequities in access and use, and develop a plan that applies the best available evidence (CDC, 2020).

The 360-degree plans would set priority goals and strategies to address services, policies, systems, and environments in multiple sectors that need re-evaluation and reform (CDC, 2020). After all, opportunities to support spousal caregivers of post-9/11 combat veterans exist within all sectors, including businesses, community-based organizations, housing, libraries, and public safety and transportation agencies (CDC,

2020). Thus, the public health focus is creating "a systemic approach to address the health of vulnerable members of society who require care and the integral informal caregivers who attempt to address these needs in every community across the country" (CDC, 2020). Implementation of these plans would ideally result in widespread availability and use of caregiver support, improved service coordination, and a firm commitment to caregiving throughout healthcare systems, workplaces, and communities (CDC, 2020).

### **Cultures**

Caregiving has a cultural element. Dilworth-Anderson et al. (2020) theorize that culture is essential to caregiving because it allows for understanding both care recipients' and caregiver's identities, norms, values, beliefs, and ways of "being" and "doing." More specifically, the caregiving experience is shaped by sociocultural contexts, only within which caregiving has personal meaning and social significance (Guo et al., 2019). Certain cultures have established caregiving as a sense of obligation that motivates the caregiver's caregiving behaviors and influences caregivers' appraisal and coping (Guo et al., 2019). It only makes sense that caring becomes intuitive and a shared aspect of all cultures (Ng & Indran, 2021). Cultural norms and values upheld by caregivers can impact the severity of compassion fatigue through their social support and resource availability (Dukhovnov & Weiss, 2017). Strong family ties and social support base could decrease the burden on individual caregivers and, consequently, on their health on the one hand, but could also mean that a strong sense of duty and attachment would leave caregivers susceptible to

compassion fatigue (Dukhovnov & Weiss, 2017). It is, therefore, necessary to address compassion fatigue with cultural specificity in mind (Dukhovnov & Weiss, 2017).

### **Societies**

Whether society honors or stigmatizes caregivers is critical as it could impact caregiving decisions (Ng & Indran, 2021). Societal perceptions may impact self-perceptions and caregiving decisions. For example, a caregiver's psychological burden may worsen if caregiving is perceived negatively or undervalued (Ng & Indran, 2021). The value ascribed to caregiving is influenced by how care is culturally constructed (Ng & Indran, 2021). Some spousal caregivers may be motivated to care for their post-9/11 combat veteran, even if they suffer from compassion fatigue, to avoid negative social sanction in the form of shame (Ng & Indran, 2021). To aid in reducing compassion fatigue experienced by spousal caregiving should be positively perceived as a virtuous act (Ng & Indran, 2021).

### **SDOH**

Understanding the spousal caregivers' susceptibility to compassion fatigue could be reduced if their social determinants of health (SDOH) were understood. Social determinants of health are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks (Walden University Library, 2023b). Structural conditions such as the social determinants of health affect people's well-being and quality of life (Donkin et al., 2018).

The SDOH consists of five domains: (i) economic stability; (ii) education access and quality; (iii) health care access and quality; (iv) neighborhood and built environment; and (v) social and community context (Walden University Library, 2023b). Out of the five domains of social determinants of health, the domain of economic stability is most often studied, mainly because of the cascading effects it has on the other four domains. Spousal caregivers' social needs must be recognized and addressed to lessen their susceptibility to compassion fatigue.

## **Economic Stability**

Economic stability is an essential social determinant of health, especially for spousal caregivers. Spousal caregivers spend significant time providing essential care to their post-9/111 combat veterans with care needs (Johnson et al., 2023). These caregiving activities often impose substantial economic costs on caregivers (Johnson et al., 2023), including their economic well-being. Spousal caregivers must curtail their employment or stop working to accommodate their care responsibilities (Johnson et al., 2023). Spousal caregivers often leave full-time employment to care for their post-9/11 combat veteran, which in turn can affect the financial resources of spousal caregivers (Liu et al., 2020), creating a domino effect, which in many cases contribute to food insecurity, housing instability, and at worse, poverty. The economic costs of caregiving for a post-9/11 combat veteran can persist long after caregiving activities end (Johnson et al., 2023).

The economic consequences of spousal caregiving of post-9/11 combat veterans include increased health expenditure, labor and productivity losses, and financial capital (Asa et al., 2020). The post-9/11 combat veteran's ill health negatively impacts the

spouse's economic condition through increased family health expenditures due to the increased need for healthcare or treatment and increased time spent caring for the veteran (Asa et al., 2020). Reducing family income, savings, and assets may lead to reduced investment in physical, financial, and human capital (Asa et al., 2020). More importantly, the economic or financial hardships experienced by spousal caregivers can exacerbate their susceptibility to compassion fatigue.

## **Education Access and Quality**

The second social determinant of health is education access and quality. Education access and quality is the availability and acceptability in concert with acceptability and adaptability. Most spousal caregivers have limited social networks and limited social participation due to the intensity of caregiving. Caregiving for a wounded, ill, or sick post-9/11 veteran is considered one of the most potent factors promoting the social exclusion of spousal caregivers from active participation in society and enhancing their vulnerability to compassion fatigue. A spousal caregiver enrolling in classes can be a preventive strategy aimed at reducing loneliness, social isolation, and social exclusion-risk factors exerting a particular effect on the health and well-being of spousal caregivers (Bonaccorsi et al., 2022).

# Healthcare Access and Quality

Healthcare access and quality is the third social determinant of health. Access to healthcare is obtaining healthcare services such as preventing, diagnosing, treating, and managing diseases, illnesses, disorders, and other health-impacting conditions (University of Missouri, 2023). Attaining good access to care means having health

insurance that facilitates entry into the healthcare system, timely access to needed care, a usual source of care with whom the patient can develop a relationship, and the ability to receive care when there is a perceived need for care (U.S. Health and Human Services, 2021).

# Neighborhood and Built Environment

The neighborhood and built environment is the fourth domain of the social determinants of health. The environment is the physical and social characteristics in which people live and represents one of the most influential factors in every single person's life (Bonaccorsi et al., 2022). The built environment refers to places and spaces constructed by humans, such as cities, buildings, open spaces, and infrastructures considered a determinant of health and well-being (Bonaccorsi et al., 2022). Veterans returning from combat often struggle with reintegration into the built environment postcombat (Hilton, 2021). For example, urban design, such as a lack of exits and narrow pathways, could trigger a PTSD event in a combat veteran (Nuamah et al., 2020). Trauma-informed architecture has emerged, focusing on creating calm healing spaces for veterans (Hilton, 2021) to help them cope with stressors and trauma (Nuamah et al., 2020). Aging VA facilities were not welcoming and failed to provide for the changing physical and non-physical needs of veterans and contradicted the critically important mission of the VA (U.S. Department of Veterans Affairs, 2016). As such, investments to improve the physical design of VA facilities include large windows with a view of nature, clearly labeled exits, wide hallways, and open and circular spaces, minimalistic designs with less furniture and light colors, and ambient features such as usage of natural

lighting, avoiding triggering odors, and noise proofing (Nuamah et al., 2020). In improving the built environment for post-9/11 combat veterans, especially at VA facilities, the veteran and the therapeutic effects benefit the veteran and the spousal caregiver.

# Social and Community Context

Social and community context is the final social determinant of health.

Community and social context are how individual, societal, and cultural factors interact to impact health outcomes (Centers for Disease Control [CDC], 2021). Social and community context affect the health and well-being of spousal caregivers via multiple subdomains and diverse pathways (Singh et al., 2021). Social support, social cohesion, discrimination, community engagement, and civic participation uniquely determine social networks and social capital, the ability to seek or provide help, the ability to cope with stress, neighborhood trust and strength of social bonds, bias and prejudice, and overall sense of goals and common purpose (Singh et al., 2021). In turn, these factors shape spousal caregivers' vulnerability to compassion fatigue.

To lessen the effects of compassion fatigue amongst spousal caregivers, researchers should address significant knowledge gaps in the subcategories of community and social context (Singh et al., 2021) that would be most beneficial to spousal caregivers of post-9/11 combat veterans. First, researchers need to conduct large-scale population-based studies on social support, increase focus on social support amongst this disadvantaged population of caregivers, and develop validated, generalizable measures of social support (Singh et al., 2021). Understanding the link between social support and

compassion fatigue can assist with policymaking. Second, future research should improve the understanding of pathways linking social cohesion/networks and compassion fatigue amongst spousal caregivers, including the role of health behaviors and psychological well-being (Singh et al., 2021). Next, discrimination and bias in healthcare hurt spousal caregivers (Singh et al., 2021). Evidence-based interventions to address health system factors, such as implicit bias and lack of cultural competence, need to be further investigated to understand how it affects compassion fatigue amongst this cohort of caregivers (Singh et al., 2021). Lastly, researchers should design and implement community-level compassion fatigue interventions and increase the representation and participation of underserved spousal caregivers in community-based compassion prevention programs (Singh et al., 2021).

# Theoretical Implications

This study was guided by Figley's compassion fatigue theory. Compassion fatigue is anyone who suffers because of serving in a helping capacity (Figley, 1995). The research question that guided this study supported Figley's (1995) compassion fatigue theory. The research question was: How do military spouses describe their lived experience of transitioning to the primary caregiver for their post-9/11 combat veteran? Based on the research question, participants were recruited from Facebook military groups. Participants collected data through demographic questionnaires and one-on-one semi-structured interviews with spousal caregivers who transitioned to primary caregivers for their post-9/11 combat veteran.

Figley (1995) formulated the concept of compassion fatigue in detail and formally explained the concept as a state of tension and anxiety related to individual or cumulative trauma narratives, including the effects of cumulative stress/burnout, which manifests itself in one or more ways such as reexperiencing traumatic events, avoiding reminders of traumatic events, or sustained arousal. However, compassion fatigue is often used interchangeably with burnout and secondary traumatic stress (STS). Figley (1995) reported that compassion fatigue and STS are interchangeable.

Compassion fatigue and burnout have two similarities and are closely related concepts that result in mental, physical, and psychological exhaustion (Pehlivan & Guner, 2018). However, compassion fatigue is separated from burnout by its sudden onset and its unique symptomatology as a direct result of exposure to the trauma of another individual (Pehlivan & Guner, 2018). Compassion fatigue occurs when the person receiving the care is not protected or saved from pain or suffering, resulting in guilt or distress; burnout occurs when the goals are not met, resulting in disappointment and loss of control (Pehlivan & Guner, 2018).

On the other hand, Figley (1995) described STS development as a 'natural side product of therapeutic interaction.' Secondary traumatic stress disorder is the state of biological, psychological, and social burnout and dysfunction triggered by the recall of patient-related traumatic memories, such as depression, generalized anxiety, traumatic events, or avoiding reminders and constant arousal (Pehlivan & Guner, 2018). Secondary traumatic stress disorder results from long-term exposure to traumatic events and stories of others (Pehlivan & Guner, 2018). Conversely, compassion fatigue is due to long-term,

intensive, and continuous care of patients, self-use, and exposure to stress (Pehlivan & Guner, 2018). Secondary traumatic stress disorder and compassion fatigue are progressive and cumulative processes that cause more severe symptoms when not relieved (Pehlivan & Guner, 2018).

Since the development of Figley's (1995) theory of compassion fatigue in nursing, it has extended to those in the helping professions and, ultimately, informal caregivers. Nevertheless, there is little information about compassion fatigue among spousal caregivers, generally, and spousal caregivers to post-9/11 combat veterans. More importantly, spousal caregivers must have the tools and strategies to identify, ameliorate, reduce, and avoid compassion fatigue and strategies for developing and implementing a sustainable institutional program to manage compassion fatigue (American Association for Laboratory Animal Science, 2023). Spousal caregivers, especially those who provide informal caregiving to post-9/11, will need to advocate for further research on compassion fatigue among this specific cohort of caregivers.

This research aimed to fill gaps in existing literature regarding post-9/11 caregiving by focusing on post-9/11 spousal caregivers and their susceptibility to compassion fatigue. Figley's (1995) compassion fatigue theory research showed that caregiving of post-9/11 combat veterans often resulted in the spousal caregiver's emotional and physical exhaustion, which often impacted their ability to care for their spouse. Compassion fatigue must be considered for analysis and discussion when understanding the nuances of spousal caregivers, which may lead to adverse physical, emotional, and psychological outcomes for the caregivers.

### **Recommendations for Practice**

The findings from this study reveal that social isolation and emotion management are synonymous with the spousal caregivers' susceptibility to compassion fatigue. The underpinnings of social isolation and emotion management, or lack thereof, must be understood to implement proper support. Social isolation was uncovered as a common theme amongst participants in this study and discussed as a subtheme of social cohesion under the fifth domain of the social determinant of health, social, and community context. Emotion management was a common theme throughout this study. Spouses discussed in detail how they grieved the loss of their spouse when they transitioned to the caregiver for their post-9/11 combat veteran, which ranked among "life's most significant stressors," evoking intense psychological and physiological distress (Wu-Chang et al., 2022). However, through emotion management, spousal caregivers were to regulate their emotions by initiating, maintaining, and modifying their emotional experience and expression (Restuborg et al., 2020).

Studies have examined loneliness and social isolation in informal caregivers, partly demonstrating a link between informal care provision and increased loneliness because informal caregiving can reduce the time available for family and friends due to reasons of prioritizing-which can result in loneliness or isolation (Hajek et al., 2021). Nevertheless, informal caregiving can also contribute to an increased size of social networks (e.g., by establishing contacts with other informal caregivers). It may reduce loneliness or social isolation (Hajek et al., 2021). While social isolation and loneliness amongst caregivers, specifically informal caregivers, provide contextualized details to

support transferability to other contexts or settings, these studies should not be generalized to spousal caregivers of post-9/11 combat veterans (Hoel et al., 2022). Social isolation and loneliness amongst spousal caregivers of post-9/11 combat veterans should be studied beyond the most common typology of spousal caregiving dyads (couple relationship, the wife being the caregiver) (Hoel et al., 2022). Specifically, studying spousal caregiving of post-9/11 combat veterans can give insight into how lack of support from the spousal caregivers' social network and the inability to participate in activities outside their homes socially contribute to social isolation and loneliness and, ultimately, compassion fatigue (Hoel et al., 2022).

Emotion management was crucial to spousal caregivers. Spousal caregivers symbolically wore "multiple situational masks" to cope with accumulated progressive losses as they adjusted to their new and evolving identities (Beatie et al., 2021). Not identifying as caregivers, many spousal caregivers-sometimes imply a sense of denial, rejection, and nonacceptance of the very idea of being a caregiver (Beatie et al., 2021). In part, this appeared to be a sign of maintaining hope, attempting to anxiety about impending decline and imbalance in the relationship, or maintaining boundaries around commitments and family obligations (Beatie et al., 2021). Research should focus on how emotion management interventions with multiple components at different phases of the caregiving trajectory may significantly reduce uncertainty and facilitate adaption amongst spousal caregiving, thus reducing compassion fatigue (Guan et al., 2021). However, researchers would need to employ a rigorous research methodology to test emotion management interventions among this caregiving population and to ensure

complete and accurate reporting of the research procedures and findings (Guan et al., 2021).

Spousal caregivers are more likely than other categories of caregivers to express a lack of choice associated with becoming a caregiver (National Rehabilitation Research and Training Center on Family Support [NCFS], n.d.). Spousal caregiving was an event that occurred involuntarily and unexpectedly (Wu-Chang et al., 2022). Typically, involuntary life transitions are more distressing than those entered voluntarily (Wu-Chang et al., 2022). Most spousal caregivers report having no choice in taking up the caregiver role (Wu-Chang et al., 2022). Transitioning into the primary caregiving role because of "lack of choice" and the by-products of struggles accepting the social expectations involved in the new role (Beatie et al., 2021). Thus, there is a need to explore further the extent to which spousal caregivers of post-9/11 combat veterans modify their self-concepts and identities (Beatie et al., 2021). A deeper understanding of the early stages of caregiver identity development of spousal caregivers of post-9/11 combat veterans could provide insight into the attributes of persons who may be more prone to adverse mental health outcomes and burnout, specifically compassion fatigue (Beatie et al., 2021).

### Conclusion

Since the conception of compassion fatigue, research has focused on compassion fatigue amongst professional caregivers, specifically nurses. While compassion fatigue has been well-documented in nursing and medical literature, research on compassion fatigue amongst spousal caregivers has paled in comparison. This study aimed to produce

new insights into how compassion fatigue impacts spousal caregivers of post-9/11 combat veterans.

While the expectation was that these spouses would seamlessly transition into this role, the participants in this study stated they were emotionally, financially, and psychologically ill-prepared for their "new normal." Spousal caregivers stated their "new normal" was void of support systems in place to help correctly transition into the role of primary caregiver, increasing their susceptibility to compassion fatigue.

This research provides opportunities for researchers, policymakers, healthcare professionals, healthcare organizations, caregiving advocacy groups, and other stakeholders to clearly understand how compassion fatigue affects the spousal caregiver of a post-9/11 combat veteran. As such, these entities can implement social, financial, and other support systems to minimize the spousal caregivers' susceptibility to compassion fatigue. Healthcare professionals should advocate and include the well-being of the spousal caregiver in the care of the post-9/11 combat veteran.

The results of this study indicated that spousal caregivers of post-9/11 combat veterans have been excluded from research, caregiving programs, and social services. I hope these initial findings will encourage others to research compassion fatigue in spousal caregivers in other military branches. More specifically, further research should explore compassion fatigue amongst spousal caregivers of post-9/11 combat veterans using a mixed-methods research design. Lastly, researchers should explore culturally sensitive interventions to reduce compassion fatigue for this caregiver subgroup.

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Appendix A: Recruitment Letter to Organizations

To Whom It May Concern:

My name is Rebecca Brown-Tuyishimere. I am a PhD student at Walden University. I am currently conducting research on the lived experiences of military spouses who transition to primary caregiver for their post-9/11 Army combat veteran. Since I have no direct access to these individuals, I am contacting organizations that specialize in caring for the mental, physical, and psychological needs of veterans, as there is direct contact with these individuals. I have attached a recruitment flyer that details the specifics of the study which include the following: (a) the name and contact information of the investigator; (b) the purpose of the research; (c) basic eligibility criteria; (d) brief list of participation benefits; (e) the commitment of the required subjects; and (f) compensation.

Spousal caregivers who meet the criteria listed on the recruitment flyer will be able to contact me by phone or email. This study will be confidential, and participants will be identified with a pseudonym. Participants in this study will help policymakers and researchers understand the experiences of military spouses who transition to primary caregiver for their post-9/11 Army combat veteran. Furthermore, participation is completely voluntary, and participants can withdraw from the study without any consequences. Please feel free to call me at 910-987-7266 with any questions or concerns you may have or e-mail <a href="mailto:rebeccatuyishimire@gmail.com">rebeccatuyishimire@gmail.com</a>.

Respectfully,

Rebecca Tuyishimire

### Appendix B: Letter to FB Military Group Administrators

Dear Facebook Administrators:

My name is Rebecca Brown-Tuyishimere. I am a PhD student at Walden University. I am currently conducting research on the lived experiences of military spouses who transition to primary caregiver for their post-9/11 combat veteran. Since I have no direct access to these individuals, I am contacting administrators of Facebook groups for military spouses. I have attached a recruitment flyer that details the specifics of the study which include the following: (a) the name and contact information of the investigator; (b) the purpose of the research; (c) basic eligibility criteria; (d) brief list of participation benefits; (e) the commitment of the required subjects; and (f) compensation.

Spouses who meet the criteria listed on the recruitment flyer will be able to contact me by phone or email. This study will be confidential, and participants will be identified with a pseudonym. Participants in this study will help policymakers and researchers understand the experiences of military spouses who transition to primary caregiver for their post-9/11 combat veteran. Furthermore, participation is completely voluntary, and participants can withdraw from the study without any consequences.

Please feel free to call me at 910-987-7266 with any questions or concerns you may have. I can also be emailed at <a href="mailto:rebeccatuyishimire@gmail.com">rebeccatuyishimire@gmail.com</a>.

Respectfully,

Rebecca Tuyishimire

### Appendix C: Research Announcement Flyer

# For Better or Worse, In Sickness and Health: The Lived Experiences of Spouses who Transition to Primary Caregiver for their Post-9/11 Army Veteran

I am currently seeking military spouses who have transitioned to primary caregiver for their post-9/11 combat veterans to take part in a project as part of my PhD at Walden University, supervised by Dr. Sandra Harris. The study aims to investigate the experiences of spouses of post-9/11 combat veterans from the spousal perspective. The study is interested in how these experiences have changed your life. Your participation is completely voluntary, and you can withdraw at any time without penalty.

### Who can participate?

Military spouses who meet the following criteria:

- 1. In a heterosexual marriage
- 2. Spouse of an active-duty Army soldier during the post-9/11 wars
- 3. Spouse is currently an Army combat veteran
- 4. Transitioned to primary caregiver for their combat veteran

### How you can participate?

Call Rebecca Tuyishimire at 910-987-7266 and complete an initial interview by phone to collect personal information.

Agree to being audio recorded during the initial interview and follow up interviews. Assist researcher in verifying the accuracy of the information you share

### What are the risks?

There are no physical risks. Your information will be held in the strictest confidence. You will be identified by a pseudonym to ensure your personal information, experiences, and thoughts will not be shared. By participating you may share personal information about your experiences that may cause emotional discomfort.

### Why participate?

This is an opportunity to let your voice as military spousal caregiver of a post-9/11 combat veteran be heard.

### Compensation?

At the conclusion of the study, participants will be given a \$25 Target or Walmart gift card.

### Appendix D: Informed Consent Form

### 1. What is the study about?

You are invited to participate in a study that aims to investigate the experiences of spouses who transitioned to primary caregiver for their post-9/11 combat veteran. It will examine and explore how having a spouse with a military-related disability impacts and changes the spouses' lives. The study is also interested in whether spouses feel as if they are susceptible to compassion fatigue.

### 2. Who is carrying out the study?

The study is being conducted by Rebecca Tuyishimere and will form the basis for the degree of her PhD at Walden University under the supervision of Dr. Sandra Harris.

### 3. What does the study involve?

The study involves participating in a one-to-one telephone interview. Each interview will be audio recorded and transcribed. During the initial interview, you will be asked demographic questions and a series of questions related to your caregiving duties for your combat veteran. These questions are very personal and sensitive.

If you agree to participate in the interview, you will be read a participant consent form giving permission for the interview to take place and be audio recorded. You can withdraw this consent at any time in the interview. The transcription shall be made available to you for review before being analyzed in the context of the research study.

### 4. How much time will the study take?

The initial interview, and post-interview will take approximately 45 minutes each, however, depending upon the progress of the interview the actual time taken may be shorter or longer.

### 5. Can I withdraw from the study?

Yes. This study is completely voluntary. You can withdraw from the study at any time without consequence and any information related to your participation will be erased and not included in the study.

### 6. Will anyone else know the results?

All participants will be identified by a pseudonym. Real names will not be used and all clearly identifying information will be removed from the transcripts.

### 7. How will the study benefit me?

Through participation in the study, you will be able to share your experiences as a spousal caregiver to your post-9/11 combat veteran to others.

### 8. Will I be compensated for my time?

At the completion of the study, participants will receive a \$25 Target or Walmart card at the completion of the interview.

### 9. Who do I conduct if I am interested in participating in this study?

Please call Rebecca Tuyishmere at 910-987-7266.

### Appendix E: Demographic Questions

It would be much appreciated if you could answer these pre-interview questions. The
reason for the questionnaire is to get to know each participant and their background.
Every participant is unique in terms of age, number of years as a spouse, and a caretaker.
Completing this questionnaire allows more time during the interview to focus on your
transition to primary caregiver.

## 1. What is your age bracket?

Under 25	
25-40	
40-60	
60+	
Prefer not to say	

### 2. How long have you been married?

Less than 5 years	
5-10 years	
10-15 years	
15-20 years	
20+ years	

3. Which best describes your household income (before taxes	S)	'!
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Under \$15k	

\$15-\$35k	
\$35-\$50k	
\$50-\$65k	
Prefer not to say	
To which ethnic group do you identify?	
African/African American/Black	
Asian	
Caucasian/White	
Hispanic or Latino	
Pacific Islander	
Other (please specify)	
Prefer not to say	
What is your highest education?	
H.S. Diploma	
Associates Degree	
Bachelor's Degree	
Master's Degree	
Doctoral Degree	
Other (please specify)	

4.

5.

	Student	
	Stay-at-Home Mom	
	Employed, Part-Time	
	Employed, Full-Time	
	Self-Employed	
	Unemployed	
	Prefer not to say	
7.	How many years of service did your husb	and serve in the post-9/11 wars?
	1-3 years	
	3-5 years	
	5-8 years	
	8-11 years	
	11+ years	
3.	How many years have you been a primary	caregiver for your combat veteran?
	Less than 5 years	
	5-8 years	

6. Prior to your current role as a caregiver, what was your employment status?

Prefer not to say

8-11 years	
More than 11 years	

9. Do you have children? If so, how many and what are their ages?

### Appendix F: Interview Questions

### **Icebreaker question**:

What is your favorite memory while you were dating? Engaged? Married?

### **Question 1:**

Describe what your life was like prior to you becoming a military wife.

### **Question 2:**

Describe your life specifically when your husband deployed to the post-9/11 wars.

### **Question 3:**

Describe the challenges you experienced when you found out your husband had military-related injuries (financial issues, employment, doctor locality, specialty, balancing schedules, etc.)

### **Question 4:**

Describe your thoughts when you found out your husband would require a full-time caregiver?

### **Question 5:**

Describe your interactions with the medical staff at the hospital, clinics, and rehabilitation centers? Did you participate in any intervention or resource programs as a spousal caregiver? Were they through a military organization?

### **Question 6:**

Describe your support system as a spousal caregiver (friends, family, other military wives, support groups, neighbors).

### **Question 7:**

Describe your everyday life.

### **Question 8:**

Describe how you feel about your husband since you become his caregiver. Have your feelings changed about marriage? Have you considered divorce? If so, why? If not, why?

### **Question 9:**

Have you ever thought about placing your husband in a nursing home?

### **Question 10:**

How has becoming a spousal caregiver changed you? Are you able to go out? Are you able to socialize with friends?

### **Question 11:**

If you have children, how has your status as a caregiver and your husband's status as a combat veteran affected them? Their relationship with you? Their father?

### **Forward Thinking Questions**

What policies or benefits do you believe should be implemented for combat veterans and spousal caregivers?

What do you foresee occurring in the next five years with your husband's injuries? This could be a medical discovery, increased benefits, a policy creation.