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Revealing Grace: The Lived Experiences of America's Post-9/11 Military Caregivers

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REVEALING GRACE: THE LIVED EXPERIENCES
OF AMERICA'S POST-9/11 MILITARY CAREGIVERS

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A DISSERTATION

Submitted to the Ph.D. in Leadership and Change Program
of Antioch University
in partial fulfillment
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This is to certify that the Dissertation entitled:

REVEALING GRACE: THE LIVED EXPERIENCES OF AMERICA'S POST-9/11
MILITARY CAREGIVERS

prepared by

Jennifer J. Hunter

is approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in
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Dedication

I dedicate this dissertation to the fourteen Elizabeth Dole Military Caregiving Fellows who so generously participated in this study. You were my gracious teachers and gentle muses.

Your husbands served our country with honor, integrity, and heroism in a new era of war we called post-9/11. To you, America's boots on the ground at home, I owe you a debt of gratitude, as does our country. Through your stories, we are reminded of our universal connection, and the pain and joy that cut through the hearts of us all.

May God bless you and keep you safe forever.

Abstract

This research focused on the lived experiences of fourteen military caregiving wives whose husbands were wounded, ill, or injured in a post-9/11 combat theater of war. All wives in this study had been vetted by and appointed to the Elizabeth Dole Military Caregiving Fellows Program and were either actively involved in the Fellowship or had become recent alumni of the two-year commitment at the time of this study. The purpose of this study was to provide a platform for their voices, understand their hopes, struggles, successes, and failures, and to give honor to their stories of military caregiving through the qualitative methodology of narrative inquiry. The stories as data were analyzed in two distinct ways. The first was using a plot analysis that exposed the story lines of the caregivers from the moment of their husbands' final deployment home to the present day, ranging from three to 13 years post onset. Using eight plot line elements, the arc of the story lines revealed one continuous story that was consistent among all caregivers, yet highly nuanced and unique. Thematic analysis was conducted as the second way of looking at the data. Moving dynamically along the flow of the story line, topical themes and their subthemes deepened the understanding and sense-making the caregivers expressed at each stage of their evolution, providing the thematic road map of each journey. It was within this roadmap that a holistic picture emerged of the wives' journey through the emergent themes beginning with hope, to their own unraveling, to disillusionment with self, other, and the system, to the factors that eventually allowed them to turn toward a more empowered self, and finally, to the paradigm shift that ultimately allowed for transformative, inspired action. This dissertation is accompanied by the author's MP4 video introduction. The electronic version of this dissertation is available in open access at AURA: Antioch University Repository and Archive, <http://aura.antioch.edu/> and OhioLINK ETD Center, <https://etd.ohiolink.edu>

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Prologue

Lt. Colonel Charles William Hunter

My father was a very patriotic man who loved this country. He used to tell the story of when he heard recruiters had come to his hometown in Traverse City, Michigan, to enlist men for the First World War. He ran to the office, hoping to be accepted into the ranks, but of course, he was a child and did not make the cut, even when he tried to stand up very straight and tall. They told him to come back another time. But, not surprisingly, he made other plans.

In the late 1930s, my father was in Burma, flight training as a volunteer with the American Volunteer Group (AVG), more popularly known as the Flying Tigers. But the AVG disbanded on July 4, 1942, when their contract was up, only seven months after the entry of the United States into World War II. A small group of men remained in China and continued to fly as part of the newly formed China Air Task Force. Nearly a year later, on March 5, 1943, the China Air Task Force became the Fourteenth Air Force Flying Tigers combat unit, heir to the short-lived, original AVG Flying Tigers. My father flew with distinction in the China Theater as a Tiger with the 14 AF until the end of World War II, reaching the rank of Lt. Colonel. This is the only exposure I have ever had with the military, until my first interview for this dissertation.

My father was older when I was born, and my mother used to say it was because we were so much alike that we could barely be in the same room together. He died in 1976, at home with my mother in Florida. I was in Colorado, and she called me the day after he had passed. I don't remember why she said she had waited.

Dad, whether you and I somehow had an unknown shared vision we could never agree upon, or were at odds with one another because it just felt more familiar that way, it has always been a deep regret of mine that I never took the opportunity or had the courage to thank you for

your devotion to this country and appreciate the person who you had to be to take on what you did during that period in our nation's history. I am indebted to your service and so proud of you.

Fifty-six years and nine days after the official end of World War II, the World Trade Center came down in a rage against the democracy for which you fought so courageously, and a different era of men and women went back to war. Once again, many lives were lost, broken or changed irreparably.

After that happened, I started thinking about you a lot and what you must have experienced in your years of service.

This dissertation is because of you. You have been with me from the beginning, guiding me, encouraging me, informing me, and now I want you to have it. The offering itself is meager, I know. But I hand it to you in thanks as a long-overdue acknowledgment of the privileges you fought to preserve in our country and for all the contributions you made in my life.

Thank you. I love you.

Introduction

The heroes don't look the way they used to
The flag is faded
And the song is quiet
The heroes don't look like they used to
They are tired
They are sad
And no one told them it was over (Comeau, 2014, p. 40) Reprinted with permission

The wounded, ill, or injured members of our armed forces who return home from combat, after having made physical or psychological sacrifices on behalf of our country, often receive recognitions, awards, honors, or acknowledgments (Ramchand et al., 2014). They are thanked and appreciated as deserving heroes in the line of duty for their service to the American people. Next to them stand the people who care for them, “an incidental population,” uncelebrated caregivers who “serve in the shadows of war” (Ramchand et al., 2014, pp. 2–3). They will help their loved ones eat, bathe, dress, and manage their daily routines. They will comfort them and be their voice. They will be a refuge, provide a sanctuary. They may even be the ones responsible for keeping their loved ones alive. Walking one step behind, they will rarely be recognized or acknowledged for the value they bring. These are our military caregivers, most of whom had dreams and plans for their lives and that of their families that did not include becoming a caregiver (Ramchand et al., 2014). They are the spouses, significant others, adult children, children, mothers and fathers, sisters and brothers, grandparents, extended family, friends, co-workers, and neighbors. They are a myriad of people in different relationships to the service member who come forward to assume the many different roles and responsibilities of caregiver. Many may not even identify themselves as a caregiver, yet that is precisely who they have become.

Of the approximately 22 million veterans who were living in the United States in 2015, roughly 4.26 million received compensation for a documented disability that resulted from a disease or injury incurred or aggravated during active military service. In the most extensive study to date on military caregivers, the RAND Corporation estimated that of the 5.5 million caregivers in the United States, at that time, at least 1.1 million people were “caring for someone who served in the military after the terrorist attacks of September 11, 2001” (Ramchand et al., 2014, p. 31), the majority of whom were wives living with their combat spouses. In comparison to the military caregivers of the pre-9/11 era, the RAND Corporation (Ramchand et al., 2014) reported these current era spouses tend to be younger (more than 40% are 18–30 years), tend to live with the individual for whom they are caring, and must navigate complex systems of health care and provisions for individuals with oftentimes multiple injuries and co-morbidities. By virtue of their age, there are younger children in the household. They are ethnically diverse, typically employed at the initial time of care giving, more than half have no connection to a support network, and at least 33% do not have health care coverage (Ramchand et al., 2014, Summary p. xviii). These caregivers are paying the price with their time, life energy, finances, health, and wellbeing. “In a separate study using data from a 2011 Gallup survey, Witters (2011) estimated that the lost productivity due to absenteeism among full- and part-time caregivers cost the U.S. economy more than \$28 billion” (Ramchand et al., 2014, p. 3). This averages out to four lost days of work a month per post/9-11 military caregiver. Yet, according to the Elizabeth Dole Foundation ([EDF], 2015), their cumulative efforts saved the U.S. taxpayers nearly \$13.6 billion in health care costs in 2015. It has been well acknowledged that military caregivers provide critical support and often long-term care at a time of rising healthcare costs mixed with increased obstacles in accessing services.

The result is that the post-9/11 caregivers frequently experience less healthy outcomes for themselves, greater stress with their family relationships, and more work-place problems, ultimately faring much worse than pre-9/11 military caregivers (Ramchand et al., 2014, Summary xviii). They are at high risk for sleep disturbances, heart disease, autoimmune diseases, depression and other mental health conditions, and “have higher mortality rates than non-caregivers” (Schulz & Beach, 1999, p. 10). This is, quite literally, the cost of their caring.

Many of our military’s wounded, ill, or injured have witnessed unspeakable events that affect them physically, mentally, psychologically, spiritually, and ethically. They come home to a new war, what Hazle, Wilcox, and Hassan (2012) call “The Reintegration War.” A war that many wounded and their caregivers and families are not winning. They are left to figure out new lives on unchartered terms. Caregivers are often left stranded with no support and no one to help them navigate hurdles. Yet too many caregivers remain silent in their own suffering with nowhere to turn. We have still come to know very little about them.

As an under-studied population, military caregivers remain largely behind the scenes, and the literature that does exist describes them in broad terms such as resilient, yet vulnerable, distressed, at high risk for and suffering disproportionately from health and mental health problems. As a nation, we are at a critical point where the time is long overdue to hear from our military caregivers. It is for this reason that my intention is to study and explore this largely over-looked population for my dissertation.

The Elizabeth Dole Foundation Military Caregivers Fellows Program

“Across this country, a quiet, untold story of profound need is emerging . . . It’s the story of America’s hidden heroes . . . women and men caring for those who cared for us. Uncertain

about their future, often alone, they soldier on with incredible strength and resilience. Today we say: "You are not alone" (Elizabeth Dole Foundation [EDF], 2015, p. 1).

In 2012, after having seen firsthand the indescribable struggles of military caregivers, Senator Elizabeth Dole founded Caring for Military Families: The Elizabeth Dole Foundation. The Foundation's mission was to raise awareness of the unique challenges that confronted military caregivers and to strengthen support for them. At that time, she also launched the Hidden Heroes Fellows Program "to engage active military and veteran caregivers directly in the Foundation's initiatives, allowing them an opportunity to advise programs and play a leading role in raising awareness for the needs of caregivers throughout the nation" (EDF, 2012a, para. 1).

According to the Foundation, 20 military caregivers were selected into the initial 2012 class. Now soon to begin its fifth year, the Fellowship, a two-year commitment, has grown to represent nearly all 50 states and Puerto Rico. These caregivers continue to be responsible for the needs of their wounded family members while meeting accountabilities as a Fellow, that today include: (a) serving as ambassadors or advocates for the Foundation; (b) advising the Foundation and the Seven Impact Councils (community support at home, education and training, employment and workplace support, financial and legal issues, interfaith action and ministry council, mental and physical health, respite care); (c) assisting in selecting grantees for the Foundations' annual Innovation Grants Program; and (d) serving as lead participants in the Foundation's efforts to lay the groundwork for a national response to the challenges of caregivers as identified by the 2014 RAND study (Ramchand et al., 2014).

Statement of Purpose

As a nation, if we are serious about caring for our military veterans, then it is time to also be serious about understanding and caring for their caregivers. These boots on the ground at home, our hidden heroes (EDF, 2015), may well be the most powerful and effective weapons the U.S. Military has. It is time now for their stories to be told.

Northouse (2013) asks, “How can a person be a leader *and* a servant at the same time?” (p. 219). I believe the question can be answered by the military caregiver. The existing research on the caregiving roles that are assumed when service members return from a combat theatre with physical injuries or illnesses, or the invisible wounds of posttraumatic stress disorder or traumatic brain injury, approaches the phenomenon from the perspective of the burden of the caregiver. Wives in particular are seen as being vulnerable to stress, anxiety, mood shifts, anger, or depression (e.g., Dekel, Solomon, & Bleich, 2005; Lambert, Engh, Hasbun, & Holzer, 2012; Patel, 2015).

However, while always acknowledging a dignified and important space for grief and suffering, I would like to shift the perspective to understand who one has to be in order to become extraordinary under these life-altering circumstances. By hearing the stories of the Elizabeth Dole Foundation Hidden Heroes Fellows, I would like to understand how such a disruptive alteration in the family, particularly within the spousal dyad, can ultimately give rise to ordinary individuals becoming extraordinary, nationally recognized caregivers to their military combat veterans.

Research Question

Military caregivers come in many different forms. For the purpose of this study, I am focusing on the most traditional relationship, which is that of the wife and her injured, ill, or wounded combat military husband from a post-9/11 theater of war.

My interest and curiosity is in hearing the stories of the life experiences of Dole Fellows who give daily care to their wounded combat veteran husbands. Riessman (1993) points out that it is especially true that the narrative form helps make sense of “difficult life experiences and trauma” (p. 4). The exploratory process of narrative inquiry will allow the natural wisdom of these caregivers to emerge and to articulate how they have made sense of their experiences.

In narrative work, there is typically no inferred hypothesis. Rather, “the specific directions . . . usually emerge from reading the collected material, and hypotheses then may be generated” (Glaser & Strauss, 1967, p. 10). It is further acknowledged by Lieblich, Tuval-Mashiach, and Zilber (1998) that narrative work is interpretive work, where conclusions will shift and change based on emergence of new materials and perspectives from the participants. Yet I hope to see themes emerge within and among the stories that can be implemented to help inform on many different levels, including the caregivers themselves, professionals and organizations responsible for the health and well-being of individuals in their professional care, and for policymakers who have the platform and influence to have a say in and could make policy changes based on the realities of the day-to-day experiences of our military caregivers.

Although my inquiry includes curiosities and questions, I respect that these narratives will be uniquely personal stories told on their own terms that cannot be defined or blocked by a set of questions identified solely from the researcher’s perspective and understanding of the

phenomenon of study. As Rollins (1985) says, “Some voices will have to be restrained to hear voices from below” (p. 16).

Significance to Theory, Research, and Practice

Challenges faced by the spousal military caregiver are complex and never linear. Therefore, within the micro context of the family, I will begin by reviewing the effects of war on combat military personnel deployed to a post-9/11 military theater of war (e.g., Iraq and/or Afghanistan) and how these effects may impact or influence the caregiver. The major categories reviewed will include the polytrauma triad (pain, traumatic brain injury, and posttraumatic stress disorder) as well as suicide. Additionally, from the perspective of the functioning of the family within the larger context of the military culture, I will review ambiguous loss, secondary traumatic stress disorder, and stigma as a barrier to mental health care for the caregiver. I will conclude this chapter with further information on the Elizabeth Dole Foundation and the Hidden Heroes Fellows Program.

At the center of this creation is the family’s emotional triangle, illustrating the emotional flow of energy that can explain sources of actions that, otherwise, may seem irrational or irresponsible. In general family systems theory, a triangle is the smallest stable relationship system. A two-person system, for example, a husband and wife dyad, typically tolerates very little tension before needing to involve another person, thereby creating a triangle (Everson & Figley, 2011). The points on the triangle for this research consist of the *combat military servicemember/veteran*, his *spouse* and secondarily the children as a subset, and the third point on the triangle is the *military*. The military is considered viable, although is a non-human entity. This emotional triangle is situated within the larger context of the U.S. Military with its culture dominated by factors such as formality, rank structure, an intolerance for mistakes, loyalty

demands, camaraderie, and emotional control. This is critical, as the hierarchical nature of the military will typically override decisions made by the military spouse for these reasons (Northcutt & Kienow, 2014). Understanding this context within which the combat military serviceman is exposed is crucial and pivotal to understanding the extent of care giving needs.

According to Dunivin (1994), “The military’s core activity is combat . . . Its primary job is to fight and win wars” (p. 2). As the primary goal of the military, it will be important to understand how the military goes about training its recruits to fight and win these wars and to understand how the military grooms their service members to function in a heightened state of physiological arousal to survive in a combat environment. The military’s ethos is deeply ingrained, pervasive, and powerful. It creates the platform that governs a soldier’s behaviors and performance expectations. Therefore, the elements of military combat-ready training and service will be critical in understanding the aftermath of what effects being in a combat theater of war may have on an individual.

The neurobiology of traumatic stress will be integrated into this review. The physiology that gives rise to conditions such as posttraumatic stress disorder (PTSD), coupled with the rigor and expectations of military training, produce brain alterations that are not psychological in nature. As a result, even the best psychotherapy cannot always affect reliable changes in the face of these physiological alterations. Schreiber and McEnany (2015) contend that traditional treatment for those military personnel entering through clinical doors continues to appear to be primarily psychopharmacology and cognitive behavioral psychotherapy, the gold standard of care of the Department of Defense (DoD). The Veterans Administration (VA) continues to provide two forms of cognitive behavioral therapy to veterans presenting with PTSD: Cognitive Processing Therapy (CPT) and Prolonged Exposure (PE) therapy. According to the Department

of Veterans Affairs, National Center for PTSD, the goal of CPT “is to understand how certain thoughts about trauma cause stress and make symptoms worse,” whereas, the goal of PE “is to have less fear about traumatic memories . . . by talking about [the] trauma repeatedly with a therapist” (2010, p. 56).

The military is steeped in tradition. *Tradition*, defined as a term, is: “any practice or custom which is generally accepted and has been established for some time within a society, social group, etc.” (“Tradition,” n.d.). These inherited beliefs, actions, and behaviors are handed down for safekeeping to ensure that values such as loyalty, duty, respect, selfless service, honor, and integrity are reinforced.

From this, opposite tensions arise. From one side, tradition grants predictability, which is a function of safety. The military can be counted on to be protective, hierarchical, paternalistic, authoritarian, tough, group-oriented, aggressive, male-dominated, physically arduous, and proud (Rothman, 2011). There is comfort and safety within this predictability. And yet, on the other side, outside of this very culture created to provide safety, there are higher than average rates of suicide, helplessness, homelessness, drug and alcohol addiction, and joblessness (Tanielian et al., 2008), largely due to the psychological effects of exposure to war, injuries, illnesses, or chronic conditions, such as pain. The military’s ethos does not embody characteristics that are easily bracketed to support mental health intervention. As a result, there does not yet appear to be any middle ground that has been gained. Most spouses defer to their combat veterans to receive mental health services first before taking care of their own needs, irrespective of the degree of need on either side.

For the combat veteran, issues of the stigma of receiving mental health services will also be addressed. Stigma is understood as a deeply discrediting attribute and consequently, rejection

is a common experience (Goffman, 1963), as are discrimination and shame, leading to avoidant behavior and an unconscious predisposition against seeking help (Drapalski et al., 2013). Wives of combat veterans face their own unique types of stigma while caring for their husbands (Phelan et al., 2011). The effect on the caregiver thus potentially has profound psychological adversity. Many caregivers are even “unprepared or unwilling to hear about the psychological impact of warfare on the veteran” (Patel, 2015, p. 10).

More and more evidence is being substantiated by research that trauma is contagious. Pearlman and Saakvitne (1995) state, “Significant disruptions in one’s sense of meaning, connection, identity, and world view, as well as in one’s affect, tolerance, psychological needs, beliefs about self and other, interpersonal relationships, and sensory memory” (p. 151) can be caused by an empathetic engagement or relationship with a spouse suffering with traumatic experiences. According to Figley (1995), these may, in fact, be “the natural and consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other”—what Figley calls “the stress resulting from helping or wanting to help a traumatized or suffering person” (p. 7). It is possible that many of these caregiving spouses are themselves suffering from secondary PTSD without realizing it. This is an area that is well researched, although there are differing points of view regarding the conditions necessary for transmission of PTSD. It will be a critical piece to add to the body of work for this dissertation.

As a term conceived by the Elizabeth Dole Foundation, *Hidden Heroes* seems very fitting and appropriate. There is truly very little that is known about the military caregiver. In 2014, the Elizabeth Dole Foundation approached the RAND Corporation to conduct widespread research “to describe the magnitude of military care giving in the United States today, as well as to identify gaps in the array of programs, policies, and initiatives designed to support military

caregivers” (Ramchand et al., 2014, Preface iii). The study concluded “11 recommendations organized around four specific strategic objectives: (1) empower caregivers; (2) create caregiver-friendly environments; (3) fill gaps in programs and services to meet needs; and (4) plan for the future” (Ramchand et al., 2014, p. 133).

Themes from the stories of the lived experiences of the Fellow recipient caregivers could have significant impact on any of the four objectives above. Being clinical by profession, I look forward to seeing what is revealed and how the themes of the stories from the Fellows can be woven into programs or offerings that could be used by others as we continue to make an impact into this critical national concern.

Limitations

An immediate limitation I see is that I am focusing my research on a traditional relationship by including only the current era wives of combat veterans and that these wives have all been appointed as Elizabeth Dole Fellows. Additionally, the assumption is already embedded that these women are extraordinary caregivers with positive identities who advise policymakers and program leaders, and that their experiences are vastly different from caregivers whose voices are not part of the public domain. I list this as an assumptive limitation because there may be military caregivers who are not Elizabeth Dole Fellows who are doing positive, significant, and productive work at the local, state, and national levels on their own or in groups they have joined or have formed on their own. Additionally, by doing research on current era veterans exclusively, it automatically eliminates the thousands of veterans and their caregivers who have come before this era.

Another significant limitation is how I was trained to listen. I am a clinical professional and, by nature, habit, and experience, I actively listen for what is missing with a focus on filling

in that blank. Perhaps it is best to keep in mind Riessman's (1993) statement that "researchers can also bear witness" and that "precisely because they are essential meaning-making structures, narratives must be preserved, not fractured, by investigators, who must respect respondents' ways of constructing meaning and analyze how it is accomplished" (p. 4).

Overview of the Dissertation

The second chapter is the Literature Review; it is a thorough literature overview and addresses the aspects of the military caregiver within the context of the family and the U.S. Military. I believe that the realities faced by military caregivers have taken the United States to the point where we are now faced with a national concern and that it is crucial to understand the framework within which military caregivers operate. The third chapter presents the Methodology used for this dissertation, the approach, and research methods. This chapter also presents rationale for the research methodology and concludes with ethical considerations. The fourth chapter is a presentation of my findings and discussion of the two different analyses used. The women's stories are presented in a disaggregated manner to showcase the analyses. The fifth chapter re-aggregates the women's stories in the form of a grand narrative. The sixth chapter presents a discussion of the data analysis results, and addresses ways that this information might inform future work with military caregivers, as implications for practice are raised. Future research considerations are also acknowledged.

Definition of Terms

Afghanistan—Operation Enduring Freedom (OEF— Operations began with U.S. military forces deployed to Afghanistan to combat terrorism on October 7, 2001, and designated Operation Enduring Freedom (OEF). On December 28, 2014, after 13 years of combat

operations, President Obama and Secretary of Defense Chuck Hagel announced the end of OEF (Torreon, 2016, p. 7).

Iraq—Operation Iraqi Freedom (OIF)— On March 19, 2003, President Bush announced to the nation that the early stages of military operations against Iraq had begun and designated Operation Iraqi Freedom (OIF). On May 1, 2003, in an address to the nation, President Bush declared that “major military combat actions in Iraq have ended, yet U.S. troops remained in Iraq for almost seven years.

On August 31, 2010, President Obama announced that the American combat mission in Iraq had ended. A transitional force of U.S. troops remained in Iraq with a different mission: advising and assisting Iraq’s security forces, supporting Iraqi troops in targeted counterterrorism missions, and protecting U.S. civilians (Torreon, 2016, p. 7).

Iraq—Operation New Dawn (OND)—Effective September 1, 2010, the military operations in Iraq acquired a new official designation: Operation New Dawn (OND). A short ceremony marked the transfer in which Army General Ray Odierno passed command of USF-I to Army General Lloyd J. Austin. On December 15, 2011, U.S. Armed Forces in Baghdad marked the official end of the war in Iraq (Torreon, 2016, p. 8).

Army Reserve—The U.S. Army Reserve (USAR) is the Army’s Federal Reserve force, providing operational capability and strategic depth to the total army in support of the National Defense Strategy and Joint Force commitments worldwide.

<http://www.usar.army.mil/Portals/98/Images/ata glance2/photos/thereservetodaybig.png?ver=2016-10-25-101051-650>).

Combat Veteran—Any GI (Government Issue) who experiences any level of hostility for any duration resulting from offensive, defensive or friendly fire military action involving a real or perceived enemy in any foreign theater (www.va.org).

Current Era—Marked by any deployment post/9-11 terrorist attacks on the United States.

Department of Defense (DoD)—An executive branch department of the federal government of the United States charged with coordinating and supervising all agencies and functions of the government concerned directly with national security and the U.S. Armed Forces. The DoD is responsible for active duty military, including medical care at military facilities (Stiglitz & Bilmes, 2008, p. 68).

Department of Veterans Affairs (VA)—Manages medical treatment and disability compensation for service members who have been discharged. The VA is divided into: the Veterans Benefits Administration (VBA), which determines eligibility for and administers a wide range of disability-related programs, and the Veterans Health Administration (VHA) which is responsible for the VA's hospitals, clinics, and other medical facilities (Stiglitz & Bilmes, 2008, p. 68).

Extraordinary—A very special thing. Very unusual, remarkable, exceptional beyond what is ordinary or usual (“Extraordinary,” n.d.).

Grace—The capacity to see and be with things just as they are, without needing to define, justify, or apologize for anything. Grace is revealed when one moves forward authentically and at will with the truth of the matter.

Military Caregiver—A family member, friend, or other acquaintance who provides a broad range of care and assistance for, or manages the care of, a current or former military service member with a disabling injury or illness (physical or mental) that was incurred during

military service. Advocates and policymakers have all proposed different definitions and eligibility criteria for military caregivers, but the term [is used] generically . . . to include anyone who serves in this capacity for any current service member or veteran regardless of whether they are related to the individual, live with the individual, or are caring for a person with injuries or physical or mental illnesses (Ramchand et al., 2014, p. 4).

Military Deployment—The movement of armed forces and their logistical support infrastructure around the world (https://www.va.gov/vetsinworkplace/mil_deployment.asp).

National Guard—The term for the state organized units of the U.S. Army and Air Force, composed of citizens who undergo training and are available for service in national or local emergencies. Entry is by voluntary enlistment. The National Guard is trained to work in conjunction with the active forces of the Army and Air Force. Units are assigned to and primarily controlled by the states (“National Guard,” n.d.).

Servicemember/Serviceman or Servicewoman—A member of the uniformed services, consisting of the armed forces (Army, Navy, Air Force, Marine Corps, and Coast Guard), the Commissioned Corps of the National Oceanic and Atmospheric Administration (NOAA) and the Commissioned Corps of the Public Health Services; someone who serves in the armed forces (www.va.org).

Veteran —A person who served at any time in any active military, naval, or air service, and who was discharged or released under conditions other than dishonorable (www.va.org).

Review of the Literature

No two hearts work harder
 24/7 to get back to each other
 One dies and the other revives
 Each beat a daunting task
 To find itself
 To find love
 This job is all consuming
 Taking all the time we have left (Comeau, 2014, p. 36) Reprinted with permission

This literature review articulates the needs faced by wives when their military combat spouses return from a current era theater of war. This chapter begins with a focus on the combat military veteran and an overview of the types of injuries that are typically seen in the theaters of war in Iraq and Afghanistan. The importance of this discussion is to create a context for the signature wounds of war and their potential side effect on the caregiving spouse. I begin with the polytrauma triad. Comprised of pain, traumatic brain injury, and posttraumatic stress disorder, this triad is particularly significant to understand if we are committed to understanding what spousal military caregivers must confront. In order to view traumatic brain injury and posttraumatic stress disorder from a lens other than psychological, I have included a section on the neurobiology of stress. Suicide, as a tragic reality, is faced too often by many caregivers, and is addressed next. I then shift focus to a discussion about the military caregiving spouses and their experiences. With this, I begin with ambiguous loss as one profound reason why it is so difficult for military caregivers to resolve their grief. This is followed by secondary traumatic stress disorder and the contagious aspect of the trauma of war. The stigma faced by both combat veteran and his spouse specifically focuses on the experiences of both. Finally, I end with the Elizabeth Dole Foundation Fellows Program and why I chose these particular military caregivers for my research.

Given the emergent nature of narrative inquiry, additional literature may be necessary to add in the sixth chapter as relevant to the findings.

Military Wives: A Brief Overview

Perhaps at no other time in modern history has the media paid so much attention to our U.S. armed services and their families. The inherently stressful demands that are unique to military life are fully acknowledged in the research at all stages of the deployment process, beginning with routine operations on home base during pre-deployment, active deployment, post-deployment, and eventual reintegration. Compounding this stressful cycle, active duty members must ensure that when it is time to deploy, they have their homes in order, finances properly allocated, bills sorted, and children's schedules arranged. They must have prepared a will and power of attorney, and be mentally, emotionally, and physically prepared to say goodbye to their immediate and extended family upon deployment (Lowe, Adams, Browne, & Hinkle, 2012, pp. 17–18).

The exhaustion associated with this on-going stress and anxiety, coupled with the apprehension of the deployed spouse's safety and well-being, often results in high rates of depression and mood shifts, stress, and anxiety among the spouses of military personnel (Mansfield et al., 2010). When multiple deployments are coupled with operational velocity, spousal "uncertainty and uncontrollability" (Rossetto, 2015, p. 251) heighten to become primary stressors during deployment.

As deployment concludes, many spouses express shifting their focus from uncertainty and uncontrollability to concerns about the health and well-being of their returning spouse and if there will be any negative effects from the exposure to the war experience (Larsen,

Clauss-Ehlers, & Cosden, 2015). For those military personnel who return altered from illnesses or injury, whether visible or invisible, the spousal stress can become overwhelming.

A family system is bi-directional, meaning all members influence and alter one another. Therefore, “each family member’s experiences and reactions to military life will reverberate throughout the system” (Lester & Flake, 2013, p. 126). When a service member returns home having suffered the effects of PTSD and/or TBI, whether diagnosed or undiagnosed often for an extended period of time, the entire balance in the family system is disrupted, creating an interactional-level phenomenon. Within this phenomenon is the vulnerability of the spouse who stands at risk for secondary traumatic stress disorder (STSD). Literature has shown evidence for secondary stress responses in the female spouses of military veterans who have been traumatized in childhood. According to Herzog and Everson (2014), these wives “have been found to have higher rates of somatic psychiatric symptoms and emotional distress. Spouses of PTSD-positive [combat veterans] are often drawn in and fused with their partner’s [symptoms]” (p. 195). Although controversy exists in the literature as to whether the spouse’s secondary traumatic symptoms are directly in response to her military spouse’s PTSD or are a manifestation of her own earlier traumatic events (Renshaw, Allen, et al., 2011), the existence of secondary traumatic stress disorder is irrefutable. Trauma is contagious (Figley, 1998) and, if left unchecked, the symptoms are at risk for multi-generational expression.

Military wives may find themselves more vulnerable and at risk to the transmission of secondary traumatic stress disorder with their military spouses returning from war zones, particularly when multiple deployments have occurred. In fact, the memories that combat military spouses bring home can be so pervasive that these memories [become] “the basis for unintentional integration of the war experience into all of the family’s processes” (Lyons, 2001,

p. 70). Here we see again the interactional-level phenomenon of STSD. The repercussions are significant, with one study finding half of the wives stating that they “were on the verge of a nervous breakdown” caused by high levels of unspecified distress (B. K. Jordan et al., 1992, p. 67). These high levels of unspecified distress are often articulated through the lens of ambiguous loss. According to Boss (2010):

Ambiguous loss is not a clear or final loss [because] closure is impossible . . . It is [confusing], painful, immobilizing, and incomprehensible so that coping is blocked . . . the traumatizing experience often continues for years, a lifetime, or even across generations . . . people are stuck alone in a limbo of not knowing. (p. 139)

Yet it is precisely these very spouses who are called upon to become the caregivers of their injured combat husbands upon their final return home.

A great deal has been written and researched about the implications of the broader caregiving population, particularly in the elderly. According to Tanielian et al. (2013), general caregiving research has typically concentrated on 50-year-old women who are managing conditions related to cancer, dementia, stroke, chronic illness, or frailty due to old age, for example. A good three-quarters of these caregivers are not living in the same home as those for whom they care. As a result, many of those cared for must rely on the efforts of adult children.

Current era military caregivers, however, are unique from the general caregiving population. Tanielian et al. (2013) flesh out the differences further by suggesting the following distinctions: The majority of these caregivers are young spouses with young children who are living with their combat veteran. These military veterans often present with complex injuries that may or may not be visible but may involve multiple, debilitating comorbidities. The military’s system of care is complicated, often confusing, and typically not centrally located. Provision of caregiving may be for a lifetime and, for some military caregivers, this could mean decades of caregiving in front of them.

However, despite different experiences between the two populations, Tanielian et al. (2013) state, “Military caregivers do share one important characteristic with caregivers of the elderly: They feel obliged to assume such a role” (p. 6).

The 2013 RAND Annual Report indicated that, between October 2001 and December 2011, just over 2.4 million service members from the Army, Navy, Marines, Air Force, Coast Guard and Reserve and National Guard units were deployed to Iraq and Afghanistan. According to the 2016 Index of U.S. Military Strength:

The Reserve and National Guard make up roughly 38% of total U.S. uniformed manpower, and their organizations provide critical combat power and support. Though traditionally supporting combat operations in a strategic reserve capacity, more recently, they have supported undersized Active [duty] component forces in long-term engagements such as those in Iraq and Afghanistan. (Dunn, 2016, p. 61)

The 2013 RAND Annual Report continued to report that roughly over a comparable period of time from October 2001 to December 2011, 63,000 service members were medically evacuated. However, this number did not reflect injuries that did not require medical evacuation. Additionally, the variance is especially wide for any estimate relating to post-traumatic stress disorder (PTSD) and does not include problems that arise or worsen post-deployment, including traumatic brain injury (TBI), mental health conditions, or health-related issues. It is estimated that upwards of 19% of [those] deployed in support of Operation Iraqi Freedom (OIF) or Operation Enduring Freedom (OEF) alone may have sustained a TBI and 31% could meet diagnostic criteria for PTSD or clinical depression (Ralveski, Olivera-Figueroa, & Petrakis, 2014). In fact, traumatic brain injury often coexists with post-traumatic stress disorder because symptoms overlap, resulting in difficulties with differential diagnosis of either. The explicit recognition of the 2007 Dole-Shalala Commission was that “the most seriously injured service members and their families are embarking on a long journey together” (Dole & Shalala, 2007,

p. 235). Therefore, it is only fitting that in order to provide for our military's veterans, we must understand and support their caregivers equally.

In order to do this, I begin with an overview of the invisible wounds of war and how any aspect of the polytrauma triad can affect combat veterans.

The Polytrauma Triad: Pain, TBI, and PTSD

According to the U.S. Department of Veterans Affairs, “polytrauma . . . describes two or more injuries to organ systems or parts of the body that create potentially life-threatening injuries and/or disruption to physical, mental, and psychological functioning” (Cifu et al., 2013, p. 1169). Pain, TBI, and PTSD have collectively been identified as the primary, most frequently seen comorbid or co-occurring war-related medical problems, giving rise to the expression of the “full polytrauma triad” (Cifu et al., 2013, p. 1170).

Pain. Representative throughout all branches of the military, pain is documented as being “one of the most frequently reported symptoms experienced by veterans returning from military action, [and is] among the most prevalent medical condition reported since the cease-fire [of the Persian Gulf War] in 1991” (Gironda, Clark, Massengale, & Walker, 2006, p. 339).

Data has shown that veterans from Iraq and Afghanistan deployments will report pain at some point either during or after military service (Gironda et al., 2006) and that these veterans may be at even higher risk for experiencing pain than those deployed to the Persian Gulf War. Injuries incurred during field operations, high explosive blast injuries, motor vehicle accidents, and gunshot wounds are all reasons documented as being associated with chronic pain (Clark, 2004; Husum et al., 2002; Nederhand, Hermens, IJzerman, Turk, & Zilvold, 2003; Richards, Stover, & Jaworski, 1990). Additionally, the need to deploy large numbers of National Guard

and Reserve units, who are typically older in age, combined with repeated, lengthy, and extended deployments, are also major factors that contribute to pain as a chronic condition.

Pain is considered chronic if it is experienced for at least three to six consecutive months (“What is chronic pain?”, n.d.). Pain may also worsen over time as one ages, and may be complicated by an inability to determine its exact source or location. Gironda et al. (2006) report that, “Extended deployment may be associated with significant psychosocial stressors that increase the likelihood of the development of chronic pain syndromes, even in the absence of an identifiable injury” (p. 342). If pain interferes with functionality and mobility, it can be a significant stressor, the management of which also falls into the hands of the caregivers.

No fully developed or empirically tested models of the co-occurrence of pain with PTSD exist in the literature today. However, as noted by Otis, Keane, and Kerns (2003), “The high rate of comorbidity and symptom overlap between chronic pain and PTSD suggests that the two disorders may be related in some way” (p. 400). However, the relationship between the two has not been fully tested and more research would be required before treatment protocols were integrated (Otis et al., 2003, p. 403).

Traumatic Brain Injury (TBI). Blasts are the leading cause of TBI (bTBI) for active military personnel (“Facts About Traumatic Brain Injury,” 2015), with the RAND Corporation (Tanielian et al., 2008) suggesting that upwards of 57% of military veterans who may have incurred a traumatic brain injury while deployed to Iraq or Afghanistan were never evaluated by a physician for a brain injury, thereby remaining undiagnosed.

The seminal work of Shivley et al. (2016) may help to clarify why there is an absence of a definitive neurological diagnosis. Shivley et al. analyzed brain specimens of male military service members with a history of chronic blast exposures. All chronic blast exposure cases

showed a distinct neuroanatomical pattern of scarring, resulting in damage to the brain that was previously undetected, and that, based on medical records, the damage persisted over the years after initial injury. These patterns of scarring were all detected in the same places, which appeared to correspond to the brain's centers for classic brain injury symptoms, including sleep disorders, headache, cognitive dysfunction, and short-term memory impairment (Shivley et al., 2016).

According to Shivley et al. (2016),

With the invention of high explosives . . . with detonations activated by heat or mechanical force that produce a shock wave . . . thousands of people . . . have had a traumatic brain injury as a result of exposure to blasts, especially in war. (p. 944)

The authors continue:

Although conventional neuroimaging for mild TBI (mTBI) typically shows no brain abnormalities, military personnel have reported persistent post-concussive symptoms such as headache, sleep disturbance, concentration impairment, memory problems (Dept of VA/DoD, 2009), often along with severe neuropsychiatric conditions including profound, suicidal depression . . . With symptoms but no biomarkers, these mTBIs became colloquially termed invisible wounds. (p. 944)

This suggests a possible reason for the clinical sequelae of headaches, sleep disturbance, decreased concentration and memory problems, particularly of blast TBI and mild TBI as being neuroanatomical rather than psychological. Today, however, these wounds continue to remain invisible, as they cannot yet be conclusively diagnosed until after death (Shivley et al., 2016).

For the caregiver of a spouse with traumatic brain injury, whether from blast, concussion, or a more severe external blow to the head, life is disrupted on many levels simultaneously, including physical, cognitive, psychological, communicative, and social. In the face of this, caregivers may feel helpless to help. TBI is an injury with profound consequences that has a way of reminding us how precious life really is. The brain is a complicated network made up to 100 billion neurons, all of which seamlessly and effectively communicate with one another.

Each area of the brain is responsible for a specific function, from emotions to heart beat. An injury to one area may cross over to the other hemisphere or radiate throughout the entire brain. These types of injuries are the most pernicious for the combat veteran and his caregiver. In all directions, lives are changed, broken, sometimes shattered beyond repair, or even lost in the face of doing the job one was trained to do.

Post-Traumatic Stress Disorder (PTSD). All military personnel are taught the necessity to suppress emotional arousal in order to effectively make sound decisions during warfare (Alford, Mahone, & Fielstein, 1988). It is well documented that in a combative experience, a heightened physiological arousal to that experience, combined with the withholding of emotional reactions, are imperative for survival. When experienced together, these are the two most critical factors that contribute to the onset of PTSD for our military personnel (Fragedakis & Toriello, 2014).

While this adaptation is critical in war, it becomes maladaptive upon returning home. Our troops are undoubtedly well prepared for duty but are often vastly unprepared for reintegration home.

Posttraumatic stress disorder is a condition triggered by witnessing, experiencing, or even hearing of a terrifying event. Yehuda (2002) states that a traumatic event has the capacity “to provoke fear, helplessness, or horror” (p. 108) in response to such as event. According to V. Hughes (2012), “acute stress triggers an intense physiological response and cements an association in the brain’s circuits between the event and fear” (p. 165). A diagnosis of PTSD is considered if the association lingers for more than a month. Military personnel who experience an amalgam of recurring loss, disaster, or violence are at increased risk for PTSD, of which the stress response may be immediate or may not manifest until months or even years later. The four

main criteria for diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) are re-experiencing the event, avoiding any triggers, negative cognitions and mood, and a heightened state of arousal (American Psychiatric Association, 2013).

According to Keane and Barlow (2002), the literature suggests, “that although the experience of a traumatic event certainly contributes to the development of PTSD, personal vulnerabilities also play an important role” (p. 398). Other factors noted by King, King, Fairbank, Keane, and Adams (1998) may include “prior exposure to traumatic events, age at the time of combat exposure, pre-military family instability, and post-military factors, including amount of social support, additional life stressors, and personal hardiness [resilience]” (p. 399). Psychosocial factors may link with personal attributes in influencing the impact of trauma, resulting in not all military personnel developing PTSD and its associative symptoms. Veterans Statistics found that “for PTSD, among male and female soldiers aged 18 years or older returning from Iraq and Afghanistan, rates range from 9% shortly after returning from deployment to 31% a year after deployment” (Veterans Statistics, 2015, Summary of Veterans Statistics para. 2).

The Neurobiology of Traumatic Stress

The neurobiology of traumatic stress moves away from psychology and character, explaining PTSD as a complex disorder involving a neurological reaction, a physiological arousal, and an emotional response (Fragedakis & Toriello, 2014). According to McEwen (2007), “The brain is the key organ of the response to stress because it determines what is threatening and, therefore, potentially stressful, as well as [determines] the physiological and behavioral responses which can be either adaptive or damaging” (p. 874). In a threatening or dangerous situation, neurological pathways in the brain signal the release of stress hormones,

including epinephrine and norepinephrine, which activate the sympathetic nervous system response known as *fight or flight* (Yehuda, 2002). Yehuda (2002) explains the implications of stress over time:

When individuals experience traumatized states for extended periods of time, an extensive wash of these stress hormones changes the structure of the brain's hippocampus, which is responsible for memories. This then stimulates an over-activation of the amygdala, which is responsible for emotions. As a result, one becomes incapable of consolidating memories and this leads to re-experiencing a visual recollection along with sensory impressions of the traumatic event. (p. 112)

This now manifests as intrusive thoughts, nightmares, or flashbacks (Brosschot, Gerin, & Thayer, 2006). Any time a trauma-related memory is triggered, even unconsciously, the individual re-experiences the event and responds on a physiological level, including increased respiration and heart rate, increased skin conductivity, and elevated blood pressure. The mind and body respond as if the trauma were continuing to occur in real time (Fragedakis & Toriello, 2014).

Studies have concluded two important facts about trauma-related stress: (a) given the potential for repeated assaults, deployments, and/or exposures, the impact of trauma is cumulative, in that the more times a traumatic event is experienced, the greater the impact; and (b) exposure to additional, different types of trauma is correlated with greater impact, thereby making trauma-related stress additive (Finkelhor, Hotaling, Lewis, & Smith, 1990; Turner & Lloyd, 1995).

McFarlane (as cited in van der Kolk, 2015) is currently studying how exposure to combat changes brain functioning in those who previously showed normal brain patterning. Presenting preliminary results from McFarlane's research, van der Kolk (2015) stated:

They found that the total number of months in combat over a three-year period was associated with a progressive decrease in alpha waves or relaxation . . . reflecting a state of persistent agitation. At the same time, the brain waves at the front of the brain show a

progressive slowing with each deployment. The soldiers gradually develop frontal lobe activity that resembles that of children with attention deficit/hyperactivity disorder, which interferes with their executive functioning and capacity for focused attention. The net effect is that arousal no longer helps these soldiers to focus on ordinary tasks. It simply makes them agitated and restless. (p. 326)

The essence of trauma for the survivor is feeling cut off, shattered, as if one is hovering over an unrecognizable life. It is a fear of conflict, of losing once again. It is trying to forget, hiding fear, rage, helplessness, and embarrassment (van der Kolk, 2015). It is easy to see how the spouses of these combat veterans become confused and filled with their own self-doubt, insecurities, emotions, and embarrassment as they try to respond and provide care as best as they can.

According to the 2013 RAND Annual Report:

Even beyond formal mental health disorders, the emotional needs of military caregivers are complex, multidimensional, and often include a profound sense of grief and guilt. Caregivers may be faced with a period of grieving the loss of the '*person [they] used to know,*' while at the same time adapting to their new role as a caregiver" (p. 11)

These sudden and often long-lasting changes in behavior and personality, while extremely difficult for the survivor, are some of the most distressing and debilitating consequences faced by spouses as caregivers. Adjusting to a new life with a loved one's altered personality can be incomprehensible.

Intimacy

In addition to adjusting to a spouse's altered personality, the trauma of war also results in bodies that have been altered due to severe injuries, amputations, burns, or loss of sight or hearing. These acquired injuries and disabilities, along with the invisible wounds of war of PTSD and TBI, can dramatically impair a veteran's capacity for intimacy (Satcher, Tepper, Thrasher, & Rachel, 2012). These physical conditions, as well as the symptoms of PTSD and the cognitive impairments associated with TBI, place an enormous strain on intimate relationships,

too frequently resulting in outcomes such as partner violence and abuse, divorce, and even suicide.

According to Mansfield, Schaper, Yanagida, and Rosen (2014), many intimate partners of combat veterans suffering from visible or invisible wounds, injuries, or illnesses often have few opportunities to express the effects these changes have on them. They continue:

Besides relationship challenges and stress associated with assuming a caregiver role, partners may endure their own psychological stress. These occurrences may be overlooked . . . as the focus is usually on the veteran and from the veteran's perspective. (p. 488)

Additionally, many wives may report feeling uncertain about who their spouse is to them now, perceiving him as another child rather than a husband, or they may question whether he is capable of being an independent adult or is instead a dependent who needs constant care (Monson, Taft, & Fredman, 2009).

Caregiver burden is defined by Zarit, Todd, and Zarit (1986) as “the extent to which caregivers perceive their emotional or physical health, social life, or financial status to be affected by their caring for their impaired relative” (p. 72). Feelings regarding their personal time, time management, satisfaction with caregiving, and energy level, are all areas that caregivers use to determine the amount of “burden” they may be experiencing. Therefore, “caregiver burden [is] a subjective appraisal” (Dekel et al., 2005, p. 72). Nonetheless, Dekel et al. (2005) continue to report that “these hidden victims suffer from emotional distress, poor marital adjustment, and high feelings of burden . . . yet [their own clinical experience suggests] high levels of perceived burden often “[resulting] in [the wives] avoiding or resisting therapy” (p. 79).

Satcher et al. (2012) conclude:

An adequate job has not been done to successfully reintegrate [these men and women] back into civilian society when they return from war. This is seen in the troubling reality of relationship strains like intimate partner violence, difficulties in parenting, divorce, partners turning into caregivers, and unique issues for single veterans in search of intimacy—all contributing to the staggering statistics on suicide. (p. 8)

According to the U.S. Department of the Army (2003), up to 75% of the suicides that have taken place in recent years are attributed to failed intimate relationships.

Keeping in mind that these wounded, ill, or injured combat veterans were sexual before they deployed to war and remain sexual after war, we owe them the means to learn to adapt to living in an intimate relationship with their visible or invisible injuries and wounds of war. And the same is true for the spouses or partners, who need nurturing in these relationships as well.

In terms of our post-9/11 combat veterans, according to Monson et al. (2009), “PTSD is strongly associated with intimate relationship problems and a number of indices of family adjustment difficulties” (p. 709). For example, the PTSD symptom clusters of avoidance and/or numbing through alcohol or drugs are more significantly associated with dissatisfied marital and intimate relationships according to Monson et al. (2009). Whereas, Taft and his colleagues (2005) found that those combat veterans who were physically aggressive towards their intimate partners exhibited higher rates of major depression, drug abuse, and war-zone atrocity exposure. These findings suggested that PTSD also plays “an important role in the association between PTSD and intimate aggression perpetration against [intimate] partners” (Monson et al., 2009, p. 708).

It is critical that the caregivers feel cared for and nurtured, as spousal dynamics may now have changed. In many instances, the caregiver may still love her husband but not view him in a sexual way. The husband, in return, may question his “suitability as a good partner or may feel like a mere burden” (Satcher et al., 2012, p. 9).

In order for the healing of the intimacy of marital relationships to begin, silence must be broken on intimacy and the sexual health needs of the caregivers of our wounded, ill, or injured veterans.

Suicide

According to the Department of Defense, “from 2005 to 2010, service members took their own lives at a rate of approximately one every 36 hours” (Department of Defense [DoD], 2011, p. 1). Yet, the Veterans Administration estimates “that a veteran dies by suicide every 80 minutes, accounting for around 6,500 suicides a year, nearly 20% of all suicides in the United States” (Department of Veterans Affairs, 2010, p. 1).

Since the wars in Iraq and Afghanistan, there has been more than a doubling of the suicide rate of military personnel, and according to Gibbons, Brown, and Hur (2012), for “young veterans between 17 and 24 years of age, the relative risk of suicide is almost four times higher than the general population” (as cited in Bryan et al., 2015, p. 633). Although there is conjecture that increased and sustained combat operations in the combat theaters in Iraq and Afghanistan have influenced this outcome, studies have continued to yield mixed results.

Within the past decade, however, there has been a strong linking between PTSD with suicidal ideation, attempts, and successes (Bryan, Clemans, Hernandez, & Rudd, 2013). Rozanov and Carli (2012) also suggest that, “Suicides are more frequent in those who develop PTSD, depression, and comorbid states due to war exposure” (Abstract p. 2504). However, this relationship remains conflicting. Further, combat veterans and military personnel who test positive for PTSD frequently report experiences that are not considered part of PTSD diagnostic criteria, such as “guilt and shame, negative changes in ethical attitudes and behavior, changes in spirituality, difficulty with forgiveness, social problems, self-deprecation, and reduced ability to

trust others” (Drescher et al., 2011, p. 154; Vargas, Hanson, Kraus, Drescher, & Foy, 2013, p. 154). As a result, the term *moral injury* is used to describe and include events or experiences where an individual learns about acts that deeply affect moral and ethically held beliefs, bears witness to these acts, perpetuates or fails to prevent them, or is unable to stop them (Drescher et al., 2011; Litz et al., 2009). Perhaps one of the most dramatic examples of moral injury in recent history is Lieutenant-General Romeo Antonius Dallaire, Force Commander for the United National Assistance Mission for Rwanda, who bore witness to one of the worst genocides of our time. He openly talks about struggling with PTSD and profound depression, which led to four suicide attempts. Now, after much time and appropriate therapeutic and medical interventions, Dallaire is able to eloquently write and speak about his experiences. He is an outspoken supporter of raising awareness of veteran mental health issues and PTSD.

Using general population studies on suicide, J. R. Jordan (2001) discussed empirical themes that acknowledge suicide bereavement as distinct from other forms of grief. As there are no known studies that specifically target the impact of suicide on military caregivers and families, literature on the general population offers a glimpse into the realities these families face when confronted with a death by suicide versus a normally occurring death. First, there is greater than average difficulty making sense of the death (“Why did they do it?”). Second, there are greater levels of guilt, blame, and feelings of responsibility for the death (“Why didn’t I prevent it?”). Finally, there are heightened feelings of rejection, abandonment, and anger (“How could they have done this to me?”) (J. R. Jordan, 2001, pp. 92–93).

Once again, looking at literature from the general population, it is noted that isolation and stigmatization are strongly felt by survivors and that others may view these family members more negatively. L. G. Calhoun and Allen (1991) state that, “Individuals bereaved by suicide

[tend] to be viewed as more psychologically disturbed, less likable, more blameworthy, more ashamed, more in need of professional mental health care, and more likely to remain sad and depressed longer” (p. 100). More research is required on this topic before any definitive statements can be made specifically about the short- and long-term effects of suicide on military caregivers and their families. Caregivers may disintegrate after a death by suicide, becoming overwhelmed by waves of intense emotions that may feel as if normal functioning for them may never return. These emotions may be clustered or occur as single emotions, such as fear, shock, grief, or anger. And on occasion, as painful as the realization may be, there may be times when a caregiver feels a sense of relief that the loved one is no longer suffering. What is known is that this is an aggressive act that can be extremely traumatic on caregivers and the family.

Common Occurrences in Military Caregivers

Of the myriad of mental health problems encountered by military caregivers, ambiguous loss and secondary traumatic stress disorder are rooted in what these caregivers find most painful.

Ambiguous loss. With the current era war signature wounds of PTSD and TBI (including blast and mild injuries), coupled with their recovery unpredictability, many caregivers are experiencing what Boss (2010) refers to as “ambiguous loss.” PTSD and TBI within the veteran population are compelling examples of ambiguous loss, where the veteran “is physically present but psychologically absent” (Dekel, Levinstein, Siegel, Fridkin, & Svetlitzky, 2016, p. 64). This chronic condition of brain instability and unstable functioning creates within the family an experience of boundary ambiguity. Spouses report not being able to define their roles properly, frequently choosing instead to fuse or “go along” with their husbands just to keep the peace and lower stress triggers. “Herein lies the source of much depression, anxiety, and family conflict”

(Boss, 2010, p. 137). Yet, caregivers report feeling guilty when attempting to become more independent or when considering their own needs first (Tanielian et al., 2013).

Boss (2010) continues to discuss ambiguous loss as a newly defined type of loss that is highly relevant to the experiences of caregivers of combat veterans. She defines two types of ambiguous loss: “The first is physical absence with psychological presence” (p. 138). In the case of the military veteran, this would be experienced during deployment, for example. The military spouse is away from the family with no guarantee of a safe return, yet is psychologically held present in the minds of the spouse and family. Or, it might further be a situation where the serviceman has disappeared, is physically missing, or a catastrophic event has occurred in the case of a death with no body to allow for closure. This is the first type of loss. “The second type of ambiguous loss is physical presence with psychological absence” (Boss, 2010, p. 138). This is exemplified in those returning home with PTSD, mild or blast TBI, illnesses, or chronic pain. All are conditions that alter the veteran in some way to the extent that some spouses report not recognizing their husbands upon return. Continuing to explain her work, Boss (2010) defines ambiguous loss as that which is “unclear, traumatic, a relational disorder, externally caused through war or illness (not by individual pathology), and is uncanny in that it is confusing and incomprehensible” (p. 138). This type of loss speaks directly to the heart of the matter, to the confusion and heartache that so many of our military caregivers experience day after day. A therapist whose husband suffered severe, traumatic brain injury asked the seminal question,

How is it possible to lose half a person? Half is dead, half remains alive . . . the uncanny story violates the observer’s trust in reality. Life may then deceive by promising substance and delivering ghosts. The doppelganger [an apparition or double of a living person] sits at the dinner table. (Feilgeson, 1993, p. 335)

Secondary traumatic stress disorder. The theory of secondary traumatic stress disorder had its beginnings in the nursing field. Termed *compassion fatigue* by Joinson (1992), a nurse,

to describe burnout in emergency room department settings, she coined the term to describe the “loss of the ability to nurture” (p. 116). Figley (1995), in writing about healthcare professionals’ experiences, envisioned the term as *secondary traumatic stress disorder*, explaining, “Professionals who listen to clients’ stories of fear, pain and suffering may feel similar fear, pain and suffering because they care. [At times] we feel we are losing our own sense of self to the clients we serve” (p. 1).

Several years later, Figley (1998) extended his reach to include non-professional caregivers by expanding his definition of secondary traumatic stress disorder:

It is not a static event but rather a systemic, dynamic process for the families. The emotional exhaustion and burnout [of spouses] . . . can lead to family burnout . . . [which] is the breakdown of the family members’ collective commitment to each other and a refusal to work together in harmony as a function of some crisis or traumatic event or series of crises or events that leave members emotionally exhausted and disillusioned. (p. 7)

Research has supported a link between spousal psychological functioning with PTSD symptoms in their combat spouses (Renshaw, Blais, & Caska, 2011). Comprehensive sets of tools have been used to assess the psychological health in spouses, such as a composite of items from multiple questionnaires (B. K. Jordan et al., 1992), to single measures of distress in general (e.g., P. S. Calhoun, Beckham, & Bosworth, 2002), to specific measures of symptoms such as anxiety or depression (e.g., Renshaw, Rodrigues, & Jones, 2008). As the linkage between combat-related PTSD and psychological functioning in spouses has strengthened, so too has the speculation about the nature of the spouse’s distress.

Much of the theorizing of PTSD and spousal impact has focused on non-specific forms of distress such as stress, anxiety, and/or symptoms of depression—generalized stress that may arise from any number of causes. There is a wide range of possibilities and reasons for spouses to report feeling distressed. Fredman, Monson, and Adair (2011) found the need to manage the

household around emotional triggers was distressing for some spouses. Solomon, Dekel, and Zerach (2008) reported decreased intimacy and lower levels of self-disclosure had damaging effects on the spouses. Other researchers suggested a pile-up of responsibilities, managing their spouse's psychological difficulties, or seeing their husbands suffer (Renshaw, Allen, et al., 2011) add tremendously to overall spousal stress, anxiety, and/or depression (Beckham, Lytle, & Feldman, 1996; P. S. Calhoun et al., 2002; Caska & Renshaw, 2011; Dekel et al., 2005; Manguno-Mire et al., 2007). As a result, it has been suggested the considerations reported here are part of being in relationship with another and could all be addressed through couples' therapy, PTSD-specific couples' treatment, or any number of therapeutic options for couples (e.g., Monson, Stevens, & Schnur, 2004).

However, a number of researchers apply terms used by mental health professionals who work with trauma to describe these spouses' emotional states, such as *secondary traumatization*, *secondary traumatic stress disorder*, or *compassion fatigue* (e.g., Dekel et al., 2005; Figley, 1995, 1998; Joinson, 1992). Figley (1995) defined *secondary trauma stress* or *secondary traumatic stress disorder* (STS/STSD) as "a syndrome of symptoms nearly identical to PTSD" that arise "due to exposure to knowledge about a traumatizing event experienced by a significant other" (p. 8). Renshaw, Allen, et al. (2011) state, "These caregivers are viewed as having PTSD-like reactions, specifically including re-experiencing or avoidance symptoms related to the event(s) experienced by the significant other (e.g., dreams [about the experience of the combat spouse], avoiding reminders of the event)" (p. 462). Figley (1995) further elaborated, "Moreover, STS/STSD is explicitly defined as distinct from the construct of 'burnout' or 'emotional exhaustion,' in that STS/STSD is a clear set of symptoms with an abrupt onset" (p. 12).

While it is beyond the scope of this dissertation to complete a critical review of the literature on STS/STSD in military caregivers, it has been substantiated that the spouses of combat veterans will vary in their reactions to living with and caring for a wounded spouse, but that the wives' health and mental health risks are greater than the general, non-caregiving population (e.g., Boss, 2010; Figley, 1998; Schulz & Beach, 1999; 2013 RAND Annual Report, 2014).

Stigma as a Barrier to Seeking Help Within a Military Context

“Culture provides the unwritten rules that inform and shape expected behavior” (Langston & Gould, 2007, p. 931). Within the context of the military, stigmatizing attitudes towards mental health care are a strong aspect of the culture, resulting in barriers to the care today's soldiers need to function at peak capacity.

Goffman (1963) originally referred to *stigma* as “the mark that distinguishes someone as discredited” (p. 87). It is understood as a deeply discrediting attribute and consequently, rejection is a common experience, as are discrimination and shame. This can be an adverse circumstance of profound psychological importance, leading to avoidant behavior and an unconscious predisposition against seeking help (Drapalski et al., 2013). For military personnel, confidentiality breaches also play a significant part in reluctance and avoidance in reporting and seeking help. According to Greene-Shorridge, Britt, and Castro (2007), current era “returning veterans reported feeling *pathologized* when diagnosed with a mental health disorder and were less likely to seek treatment if they saw themselves as responsible for their condition, either through deed or weakness of character” (p. 55). Yang et al. (2007) hypothesize that stigma “threaten[s] the loss or diminution of what is most at stake and what is threatened” (p. 111). In

the case of the military veteran, what is most at stake is maintaining the military's culture of silence for the sake of loyalty to the team.

Social and institutionalized stigmas are enmeshed with one another, perpetuating a vicious, looping cycle. Anyone who challenges the military's culture of silence is suspect in the eyes of the team. Those who do not seek help, regardless of the need, are often highly suspicious of those who do.

Dunivin (1994) states that, "Soldiering has [always been] viewed primarily as a masculine role because combat has generally been defined as men's work. Consequently, a deeply entrenched cult of masculinity [still] pervades U.S. military culture" (p. 2). The military's traditional combat masculine-warrior paradigm is the foundational piece that explains and influences how the United States military views what a soldier is today and how their forces are trained. There is the belief that "manning up" is the only way to fit in and belong, with the highest value being placed on group cohesion. Within a hierarchical and authoritarian system, loyalty, strength, and self-sufficiency are at a premium. Rasmussen and Zaglifa (2013) reinforce that "interdependence is crucial to the survival of service members, often demanding blind trust in one another" (p. 175). Yet, according to Yarvis (2011), "40% of military personnel, although aware of their own or someone else's . . . stress would not trust *any* person-under-stress as an effective soldier" (p. 54).

Thus, stigma creates an invisible burden that compounds seeking mental health help for the symptoms of an injury. Some studies, according to Wallace (2012), report that stigma is even more fatiguing and difficult to overcome than the injury's symptoms themselves.

Hazle et al. (2012) talk about The Next War as The Reintegration War (p. 229) and the extraordinary challenges confronting returning servicemen and their families. When a

serviceman is wounded or injured with a TBI, PTSD, or resultant chronic pain, the reintegration can be a daily, debilitating struggle. Servicemen also suffer greatly from the ethical fall-out of war, making moral injury as devastating as physical, psychological, or cognitive injuries. Caregivers frequently take their cues from their husbands and, if the veterans do not seek professional help, the spouses are likely not to seek help either. Unfortunately, the caregiver's role is too often undermined by either the veteran's stigma of seeking help or the spouse's own stigma (Larson & Corrigan, 2008). [Service members hear] "We can help!" from the mental health providers, while at the same time being told, "If you're broke, we'll kick you to the curb," from their command and the rest of the military community (Finley, 2011, p. 110).

This is the paradox of the military culture, causing service members to suffer disproportionately as a result. Seeking help, in particular mental health help, is the exact opposite of military values that espouse group loyalty, toughness, and resilience. To acknowledge experiencing a problem with mental health is an admission of weakness or failure, cowardice, or social flaws. Thus,

Service members get caught between the dual messages of the destigmatizing efforts of official military policy, which has increased accessibility to evaluation and treatment, and the culture of military life, which places priority on completing the larger mission above the well-being of any one individual. (Finley, 2011, p. 114)

Even once separated from the military, the stigma of receiving mental health services for issues related to TBI, PTSD and the co-morbidities that result often continue (Iversen et al., 2011). For their caregiving spouses, there is often the recognition of embarrassment and fear of mistreatment and negative perception.

The stigma faced is often not without validation or merit. According to Rowan and Campise (2006), "39% of service members who were referred by their commanders and 3% who self-referred for mental health treatment [were] found to experience a negative career impact"

(p. 114). Additionally, Hooyer (2012) noted cases of service members “who sought mental health treatment, only to be misdiagnosed with mental illnesses related to ‘preexisting conditions’ [that were reported] as having predated military service, such as anxiety disorder and personality disorder, and were discharged without benefits” (p. 114). Stories such as these are extremely influential and have a profound impact on servicemen and how they will proceed with their own care. For their caregiving spouses, they are typically at the effect of the decisions made by their husbands while they, too, experience their own stigma, as characterized by psychological distress.

Military caregiving spouses may not be familiar with or comfortable with the clinical sequelae associated with TBI, PTSD, or chronic pain, and may experience their husbands’ in contrary ways or unconsciously hold negative attitudes towards them (McLellan, Bishop, & McKinlay, 2010). Since the physical effects of injury, particularly with more moderate-severe TBI, are often noticeable to others, stigma and discrimination from others towards the serviceman may contribute even further to the caregiver’s emotions, causing a cascade of physiologic reactions contributing to anxiety and other negative mental health outcomes (e.g., Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Werner, Aviv, & Barak, 2008). It has been reported that military caregivers often “feel they are being treated differently [discriminated against] because of their husband’s condition or that they feel obligated to conceal or explain their husband’s condition” (Patel, 2015, p. 10). Perceptions of feelings of discrimination were “significantly associated with depression, anxiety, isolation, and caregiving strain. The need to conceal the veteran’s condition was associated with isolation from others, strain with the caregivers, and a higher rate of depression” (Patel, 2015, p. 10).

The Elizabeth Dole Foundation

In 2013, the Elizabeth Dole Foundation entered into a strategic partnership with the Wounded Warrior's Project in support of the goal to complete the first comprehensive, evidence-based research that had ever been conducted on military and veteran caregivers. Dole explained, "I am trying to inspire organizations and Americans all across this country to support these hidden heroes because their stories really are not known across America. And these are the very people who are caring for those who cared for us" (EDF, 2012b). The RAND Corporation was tasked with completing a comprehensive needs assessment that would allow the nation to be informed about programs and initiatives that were currently in place for military caregivers, where gaps existed, and to lay the groundwork for a national, strategic response to this crisis of caregivers in desperate need of stronger support. In April, 2014, RAND released *Hidden Heroes: America's Military Caregivers* nationwide, followed by the launch of the Foundation's National Coalition from the White House, calling the nation to action ("The 2015 Hidden Heroes Coalition Summit," 2015).

The Elizabeth Dole Fellows Program and the Hidden Heroes Coalition represent the best practice of a holistic approach to this critical problem, bringing together stakeholders from the private, public, nonprofit, labor, and faith communities to identify solutions and commit resources to address the needs and gaps as identified by the RAND 2014 study.

Any appeal to military service in the eyes of future generations will rest on our country's commitment to supporting all service members and veterans, including their families and caregivers, equally. Through the Fellows Program, the Elizabeth Dole Foundation is the first to offer a national platform for the voices of military caregivers to represent all caregivers. These people continue to inform us. They articulate their needs, raise awareness, and fill in the gaps to

help us understand firsthand the challenges they face as military caregivers. Through their stories, they will help us understand their life experiences, their dreams, successes, failures, and commitments. These military caregivers, vetted and appointed to become Elizabeth Dole Fellows, represent the highest level of achievement in what is possible for a military caregiver. They will help us understand how to care for our veterans better and what we need to do to create a legacy of military caregivers who are recognized, understood, supported, and appreciated.

Methodology

There is a dawning realization taking hold in the United States now that military caregivers are not extraneous and can no longer be considered incidental to their combat veteran spouses. Therefore, the purpose of this research was to study the lived experiences of military wives who find themselves in caregiving roles to their wounded, ill, or injured husbands, after having returned home from a current era combat theater of war. Through narrative inquiry, a place for their voices will be provided where we can hear, understand, learn from, and give honor to their stories. It is hoped by studying the lived experiences of military caregivers through the qualitative methodology of narrative inquiry, that a deeper understanding of this population will be revealed to realize new possibilities, inform clinical practice, and further support the groundwork needed to direct a national response and call to action. After all, Spanbauer (1999) reminds us, “The only thing that keeps us from floating off with the wind is our stories. They give us a name and put us in a place, allow us to keep on touching” (p. 35).

The word *narrative* derives from the verb *narrate*, whose Latin root, *narrāre* means to relate or recount (Narrate, 2003). It is not the actual story itself but the way in which the story is told that becomes the narrative, yet the two terms are used interchangeably. In a series of events, combat military personnel are injured in an instant, yet the narrative accounting of this event may be told over a lifetime and focus on only one or a few aspects of the actual event. Lieblich et al. (1998) believe that, while the construction of stories centers around a basic set of facts or life events, there is much room for individual freedom and creativity in these “remembered facts.” The authors continue by stating that a life story that is recounted is “but one instance of *the* life story, a hypothetical construct” (p. 8).

Narrative Inquiry as a Research Base

The few studies that have been conducted on military caregivers have been largely quantitative in nature. The emphasis has been on establishing a baseline of information around military caregivers, including gathering statistics about their demographics and determining the gaps that exist in services. This data has been critical for knowing where to begin as we look ahead and understand where and how to plan our next strategic steps. Bruner (1986) addresses the fundamental difference between the scientific and narrative ways of knowing as, “where science concerns itself with the establishment of truth, narrative’s concern is to endow experience with meaning” (p. 39). In other words, quantitative research is often thought of as “hard” research, quantifying problems using measurable, numerical data. Qualitative research, on the other hand, is frequently stereotyped as “soft,” but Bleakley (2005) warns, “Narrative inquiry’s soft data can illuminate hard realities” (p. 535).

According to Connelly and Clandinin (1990), an award-winning, leading scholar in narrative inquiry, “Narrative is a way of characterizing the phenomena of human experience” (p. 2) by understanding the history, culture, character, personality, and identity of the narrator. Its study is now seen as appropriate to many social science fields. Riessman and Speedy (2007) describe the “cross-disciplinary nature of narrative inquiry [as] a 20th century development, no longer fitting within the boundaries of any single scholarly field” (p. 427). The authors continue by stating the “narrative turn” or this “turn to language” is evidenced by the use of narrative as a base of inquiry, now having “entered history, anthropology and folklore, psychology, sociolinguistics and communication studies, cultural studies, and sociology” (p. 427). As a result of this expansion and rapid rise in interest, there continues to remain disagreement on an exact

definition of narrative inquiry. Connelly and Clandinin (2006) offer the following definition, to which they state there is “some agreement”:

People shape their daily lives by stories of who they and others are and as they interpret their past in terms of their stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study. (p. 375)

Most significantly, listening to the stories containing traumatic experiences of military caregivers will likely “throw into relief our [own] routine and taken-for-granted expectations” (Crossley, 2000, p. 528). The author continues, “When such a sense is disrupted through traumatization, the importance of narratives . . . comes into effect, as the individual attempts to reconfigure a sense of order, meaningfulness, and coherent identity” (p. 528).

Mayer (1994) describes the “early casualties of [her] twin illusions of safety and time” at the moment of her traumatic experience, and that “the more catastrophic [the event], the more urgent is the need to mine it for meaning and life-changing potential” (p. 540). As a result, a traumatic life experience is instrumental in helping to move towards an appreciation of the way in which human beings customarily construct their narratives. Narratives allow a container for worlds that have become dismantled.

Framing Narrative Inquiry

Clandinin and Rosiek (2007) frame narrative inquiry within a Deweyan ontology of experience, whereby “experiences belonging to the world are the product of discrimination . . . [and are] transformed through the human context they enter (Dewey, 1981, p. 251)” (pp. 39–40). Dewey’s ontology is defined as transactional, such that “our representations arise from experience and must return to that experience for their validation” over and over again as a

continuously moving experiential process. Represented on a continuum of time, “an honest empirical method will present inquiry as a series of choices” (Clandinin & Rosiek, 2007, pp. 39–40).

Clandinin and Huber (2010) frame narrative inquiry into three dimensions, or “commonplaces,” as a way of understanding: temporality, sociality, and place, all of which should be “simultaneously explored, [thereby] distinguishing narrative inquiry from other methodologies” (p. 3). Attending to temporal points on a continuum shows that “we [narrator and researcher alike] are composing and constantly revising our autobiographies as we go along” (Carr, 1986, p. 76). By sociality, Clandinin and Huber refer to the social conditions that hold experiences and events, understood in terms of “cultural, social, institutional, and linguistic narratives” (p. 4). Embedded in this dimension of sociality is also the relationship between the narrator and researcher. Finally, Connelly and Clandinin (2006) define place as “the specific, concrete, physical and topological boundaries of place or sequences of places where the inquiry and events take place . . . recognizing that all events take place some place” (pp. 480–481).

Attending to these commonplaces, Clandinin and Huber (2010) suggest that we are able to “study the complexity of the relational composition of peoples’ lived experiences both inside and outside of an inquiry and, as well, to imagine the future possibilities of these lives” (p. 3).

A Typology of Narrative Inquiry

The two underlying assumptions of narrative research are first, there are no single or absolute truths in human reality, and second, there are no correct ways to read or interpret the data of this reality (Lieblich et al., 1998). Stories, being individually created human experiences, limit objectivity. Therefore, Lieblich et al. call for researcher responsibility. Offering a typology for organizing and systematizing narrative data, the authors present a way for researchers to

provide a “coherent rationale for their choice of methods as well as a clear exposition of the selected processes that have produced their results” (Lieblich et al., 1998, p. 2).

In the myriad ways of reading, interpreting, and analyzing life stories, Lieblich et al. (1998) have recognized “the emergence of two primary, independent dimensions: a) *categorical* versus *holistic* approaches, and b) *form* versus *content*” (p. 12). From a categorical perspective, there is a disaggregation of the original story, where the narrative is dissected into sections or categorized by words. According to Lieblich et al. (1998) the categorical-content approach is defined by categories. “Separate utterances of the text are extracted, classified, and gathered into these categories [or groups]” (p. 13). The authors continue by explaining that the categorical form mode of analysis “focuses on discrete stylistic or linguistic characteristics of defined units of the narrative” (p. 13), and present the use of metaphors or active versus passive use of voice as examples. Bleakley (2005) summarizes the first approach of categorical content as “what happens in a particular episode of a story, analyzed for structure” and summarizes categorical form as “how a particular episode of a story occurs” (p. 537) from a stylistic perspective.

Conversely, a holistic perspective does not disaggregate the data into discrete units of analysis. Life stories are viewed and held as whole and complete, where “sections of the text are interpreted in the context of other parts of the narrative” (Lieblich et al., 1998, p. 12). The method of holistic-content follows this line of explanation by looking at the properties of the themes that emerge while always retaining the context of the entire story. The holistic-form method of analysis looks for plots or whole life structures, such as turning points “to shed light on the entire development” of the story line (Lieblich et al., 1998, p. 13). Bleakley (2005) summarizes holistic content as “what happens in a story, appreciated as an overall pattern,” and

holistic form as “how the pattern of a story unfolds, taken in context” (p. 537). My approach with using narrative inquiry for this study maintained a holistic-content perspective.

Pinnegar and Daynes (2007), in writing about *turns* or the strategic ways of thinking about narrative inquiry, suggest:

In the turn toward narrative, no change in direction is more important than the change in an understanding of the relationship of the researcher to the researched . . . [this] turn is characterized as a movement away from a position of objectivity . . . toward a research perspective focused on interpretation and the understanding of meaning. In turning, narrative inquirers recognize that the researcher and the researched in a particular study are in relationship with each other and that both parties will learn and change in the encounter. (p. 9)

Thus, I explored the whole story within the context in which it unfolded. I focused on the elements within plot lines and the themes and patterns that emerged from the story itself. This approach required a deep immersion into the meaning, texture, and emotion of the narrative as it reflected the narrator’s perspective of her experience. This immersion called forth my own opinions about caregiving, how I believed the experience would occur for me, how I would respond, and what I would make my experience mean. Having had decades of professional experience working with the traumatically brain injured young adult population, I have seen the spectrum from positive to negative outcomes, and I found myself curiously biased by this information. At times, it was also difficult for me to understand the military culture with its hierarchical organization steeped in patriarchy and lack of acknowledgment for those who care for our wounded, ill, and injured. However, my commitment to this research process was to take a step back, stand in wonder, and let the things of the world be in charge.

Method of the Study

Narrative inquiry is not guided by a specific hypothesis. The intention is to bring voices forth and allow the story itself to build the meaning and significance of the experience, unfolding

around the meaning of the participants' experiences as caregivers. As these were not my stories, I remained open to whatever arose and was spoken. The purpose of the stories was to listen and discover what new possibilities and contributions the narratives of military caregiving wives could make to clinical practice, policy, and to our overall appreciation for the experiences of others.

Participants. Fourteen interviews were conducted in unstructured, open-ended, audiotaped telephone interviews via Free Conference Calling. Of the 14 interviews, one was conducted with a participant whose husband had suffered an injury while working stateside as a non-combat veteran. Given that her story was consistent with the plot analysis, there was nothing in her story that changed my analysis. Therefore, my ethical position was to honor the fact that she had shared her story with me. This story remains in the database and her vignette is presented in the study.

According to Ms. Laurel Rodewald, the Elizabeth Dole Foundation's Programs Manager, the Foundation's criteria for selection stipulates that potential Fellows

must be from an open state [where no other Dole Fellow is actively serving], an active military or veteran caregiver, willing to be an advocate for the 5.5 million military and veteran caregivers nationwide. They should be comfortable telling their story to the media and their congressional representatives, and be willing to let people into their lives. (personal email communication, March 28, 2017)

She further stated,

We also look for people who are passionate and want to work on a local, state, and national level to affect change . . . based on their current work with other non-profits, their application answers, and their interviews with us. We do not require them to have experience working in their community—we like to empower them to do so through this Fellowship—we just want them to have the desire and motivation to make a difference. For the application process itself, potential Fellows fill out a survey with basic background details and short answer questions, submit a letter of recommendation, and participate in an interview with our Fellows Program Coordinator. (Laurel Rodewald, personal email communication, March 28, 2017)

All the women in this study had been vetted by and appointed to the Elizabeth Dole Fellows Program, the heart of the Foundation’s work, and were located across the United States. Eight of the Fellows in this study were still actively serving their two-year commitments, six were alumni. As Fellows, in addition to their daily caregiving responsibilities at home, they were tasked with directly advising the Foundation’s initiatives, giving guidance to programs, and raising awareness at local, state, and national levels to caregiver needs across the nation. The Fellowship Program is now entering its fifth year.

Table 3.1 represents a demographic overview of the study participants and their husbands’ military service. Letters were used to represent each participant, as I did not want the details of the women and their husbands to provide any possibility of identification.

Table 3.1

A Demographic Overview of Study Participants and Their Husbands’ Military Service

Participant	A	B	C	D	E	F	G
Current status	Alumni	Active	Active	Active	Active	Alumni	Active
Years married	14	13	12	8	11	14	4
Age decade	40s	30s	40s	30s	40s	40s	30s
Ages of children	13, 9	8	23, 18	14, 12, 8, 3	21, 15	15, 14	17
Living in household	4	4 (live-in caretaker)	3	6	3	7 (but varies)	3
Hrs work - employed	40 in the home	40 outside the home	N/A	N/A	14.5 (9 months only/year)	N/A	N/A
Highest education	Master’s	2 Master’s	BS	Master’s	BS	BA	Tech school
Hx of military family	Yes	Yes	No	No	Yes	Yes	Yes
Spouse’s branch of military	Navy	Army	Army National Guard	UMSC	Air Force/Army	Army	Army
Service years	1998–2003	2002–2009	1986–2006	2000–2012	1999–2013	1999–2010	1996–2004
Number of deployments	4	2	1	3+	3	3+	4+
Approx	8–10	12–15	18	Varied	6–18	9 months	6–14

length	months	months	months		months		months
Rank upon discharge	E5	E5	E6	E5	E5	E5	E6
Nature of injuries	PTSD, TBI, deaf, migraines, balance	PTSD, TBI, chronic pain, sleep apnea, balance	TBI, PTSD, hearing loss	TBI, PTSD, chronic pain, leg amputation	Facial injury, TBI, PTSD, chronic pain	Burns, TBI, PTSD, spinal	Seizures, TBI, severe PTSD
Employed outside home	No	No	No	No	No	No	No
Highest education	Military tech school	Some college	Some college	HS	BS	Some college	Some college
Hours of caregiving given	Varies	Weekends full time	30–40	65+	24/7	24/7	65+

Participant	H	I	J	K	L	M	N
Current status	Active	Alumni	Alumni	Active	Active	Alumni	Alumni
Years married	38	19	11	10	8	9	44
Age decade	50s	40s	30s	30s	50s	30s	60s
Ages of children	2/ 23+	19, 15, 9	16, 14, 10, 4-yr old twins	9	34, 27, 23	8	2/30+
Living in household	2	4	7	3	3	3	2
Hrs work-employed	N/A	N/A	Varies from home	Varies from home	F/T student	Varies from home	Varies from home
Highest education	HS	College	College	AA	College	BA	Master's
Hx of military family	Yes	Yes	No	Yes	Yes	Yes	Yes
Spouse's branch of military	Navy	Army	USMC	Army	Army	USMC	Army
Service years	1977–2014 onset 2004	2001–2012	2002–2006	1998–2010	1999–2013	2000–2013	1972–2006
Number of deployments	Multiple	3	1	2	4	5	0
Approx length	7–9 months	6–15 months	6 months	13 months	9–12 months	9 months	N/A
Rank upon discharge	SMSGT	E5	Corporal	E4	E6	E6	E8
Nature of injuries	Constrictive bronchiolitis, IBS, OTSD, skin cancer	PTSD, TBI, chronic pain, thumb	PTSD, TBI, temporal lobe epilepsy	Severe PTSD, TBI	TBI, PTSD, chronic fatigue	PTSD, TBI, physical	Chronic nerve, back, leg pain

	amputation						
Employed outside home	No	No	No	No	No	No	No
Highest education	Some college	College	HS	HS	Some college	HS	College
Hours of caregiving given	24/7	40+	65+	70+	30+	30+	24/7

Although Elizabeth Dole Fellows were specifically chosen for this study, reestablishing a sense of order and connection is an important outcome for the narratives of all military caregivers when faced with a traumatic disruption in life. Through the narratives of the Fellows, I trusted that a holistic picture would emerge as either an authentic representation of all military caregivers or would either reveal or further substantiate the gaps in military caregiver needs.

There is no agreed-upon literature as to an appropriate number of participants in a qualitative study to meet the criteria for rigor, although a minimum of 12 interviews is generally recommended in order to reach saturation of the stories. As this study was designed to meet rigor and trustworthiness, at the conclusion of 14 interviews, it was determined that the essential plots and themes had been saturated with rich detail and texture of story, and no further interviews were conducted.

Procedures for inviting participants. Since the inception of the Elizabeth Dole Foundation Military Fellowship Program in 2012, approximately 100 caregivers were identified as meeting the research criteria of being wives who were living with and caring for current era combat veterans. All current-standing or alumni caregivers who met criteria were personally invited by Ms. Laurel Rodewald to participate in this study via an emailed invitation with a short description of my study attached. It was determined that her invitation would be the most effective and appropriate way in which to introduce the study and obtain participation. Once interested participants contacted me, I responded to all inquiries by answering questions, sending

out the Informed Consent Form and the Demographic Questionnaire, and setting up the interviews.

Interviewing. According to Riessman (2008), stories are “co-produced . . . in spaces between teller and listener” (p.105) where “topics and meanings are negotiated” [between the two] (p. 40) as in a conversation. Greater conversational equality comes from interviews that are not structurally fixed, although my preference was to ask questions that stimulated topic discussion. My opening question, as frequently used by Riessman (2008) was: “How did you first become aware that you needed to become a caregiver for your husband?” Follow-up probes were used to continue to elicit the stories. For example, continuing to incorporate Riessman’s (2008) suggestions, these probes often included, “Tell me what happened. Can you remember a particular time when . . . Tell me why that particular moment stands out for you” (p. 25).

The initial interviews lasted a minimum of 60 minutes. Some Fellows were contacted afterwards via text or email for clarification purposes, and one was contacted again directly by telephone. The interviews were conducted at a time and day that accommodated the participants’ busy schedules. Prior to any contact, each participant was emailed an Informed Consent Form that had been approved by Antioch University’s Institutional Review Board, along with a brief Demographic Questionnaire. On behalf of the Elizabeth Dole Foundation, Ms. Rodewald was also emailed a copy of the Informed Consent Form for their files, as I felt it was appropriate for them to review what I was sending their Fellows. Prior to any interview, I ascertained that both participant and I had our respectively signed copy of the Informed Consent Form, each participant had read the Informed Consent, had all her questions answered, understood her participation was voluntary, and that she could withdraw at any time without any repercussion to her status as an Elizabeth Dole Fellow.

Narrative analysis. The holistic-content approach to analyzing narrative inquiry, as presented by Lieblich et al. (1998) above is interpretive work and inter-rater reliability is not an expectation or end result. During the storytelling, any disturbances or difficulties noted in the participant, repetitions, deletions, and types of details spoken are all worthy of being noted for what is said as much as for what is not said. Beginnings and endings of themes were noted, contradictions in speaking, and transitions or turning points in the storylines. This information was continually recorded in field notes written during and after each interview.

The interpretive form. I approached the narratives looking through the lenses of both plot analysis and thematic analysis. To begin with the plot analysis, I began by summarizing each participant's transcript into a one to one-and-a-half page vignette. According to Daiute (2014), "Plots are like lenses that guide perception, memory, and interpretation of the dramas of life . . . [the] narratives of life experience make sense in part because of plots" (p. 114). In the spirit of narrative inquiry, each participant was emailed a copy of the one to one-and-a-half page vignette that I wrote after reading and listening to her transcript that summarized the progression of the elements that created the structure of her story, or plot line. With this, each participant had the opportunity to read and comment on my interpretation as I had understood and written her vignette, correcting, deleting, or expanding any aspect that she felt important to reflect her story as authentically as possible.

Using Daiute's (2014, pp. 139–140) model, the plot analysis was organized around the following elements:

1. The setting—where the action took place
2. The characters—major actors in the narrative
3. The initiating action—action that motivated the plot

4. The complicating action—what actions built from the initiating action
5. The high point—pivotal conflict of the plot
6. Resolution strategy(s)—attempts to resolve the main plot issue
7. Ending—settling the conflict beyond attempting to resolve it
8. Coda—a reflection, the moral, the discovery, or transformation.

The analysis of plot revealed insights into what and where the participant's narration attended that was not necessarily recognized from a surface level, making plot analysis “a systematic way to identify the deep structure of narrative meaning [or in other words,] the skeleton of meaning” (Daiute, 2014, pp. 119, 123).

Once the individual plot structures were completed, an integrated master analysis was created, rigorously bringing in plot elements with additional thematic comments as a way of helping to summarize the progression of the storylines with their corresponding themes.

This comprehensive or overarching storyline included “propositions that [reappeared] in the form of thematic assumptions taken for granted by the [narrator]” (Riessman, 2008, p. 68).

In the spirit of thematic analysis, I extracted aspects of the caregivers' stories from their transcripts to begin the process of building a coding base. For coding purposes, multiple passes were made on the data to pull out the themes that were attached to words or phrases. Themes that ran throughout one narrative crossed many narratives as well. Connecting the stories, I discovered what Riessman (1993) refers to as “a transformation in identify” (p. 35), linking commonalities in the journey to self-realization.

This comprehensive or overarching storyline included “propositions that [reappeared] in the form of thematic assumptions taken for granted by the [narrator]” (Riessman, 2008, p. 68).

For example, these taken-for-granted thematic assumptions with the military caregiver included themes such as hope, beliefs, disillusionment, grief, loss, depression, children, finances, advocacy, inspired calling. These assumptions then provided guidelines upon which to frame the entire story. Riessman (2008) refers to this as finding a “common pattern of embedded assumptions, and also a common sequence of episodes—a kind of overarching master narrative” (p. 68). Recurrent themes or assumptions were subsequently noted and recorded across narratives.

Findings from plot and thematic analyses allowed me to re-aggregate the stories and bring them back together to tell a grand narrative in honor of these women in the fifth chapter. This process allowed me to come full circle from the time of the thought of doing this study, to the literature review, my first contact with the Dole Foundation, the selection process, interviews, analyses, and finally, my conclusions and implications for practice. More nuances were added along with my own reflections.

Reflexive journaling. Reflexivity offered the opportunity to examine how my history, upbringing, clinical experiences, and values affected and even transformed the interpretations of the stories I heard. For the purposes of this study, this occurred primarily as introspective and intersubjective reflexive journaling (Finlay, 2002).

Through personal introspection, I continually drew on my own personal experiences to help make sense of the stories I was hearing, while being aware of the intrusion of my biases and opinions. I examined my experiences and reactions to the stories told, how they affected me, what I was making the information or experiences mean, and what opened up to me as a result. Finlay (2002) comments that, “Reflections are assumed to provide data regarding the social/emotional world of participants” (p. 214), thereby contributing to the greater analysis.

Intersubjective reflexivity was a dynamic way of examining my relationship to other. This gave consideration to the unconscious interactions or processes that were likely to occur between the participant and myself as researcher. In understanding my own motivations and behaviors, I overlaid them onto the relationship and began to understand the other.

These are the types of reflections I was engaged in throughout the process of this dissertation, which acted as advancements to broader interpretations and insights.

Criteria for Rigor

In line with the constructivist paradigm that “all knowledge is constructed [and] constructed knowledge is never perfect” (Loh, 2013, p. 5), Elliott, Fisher, and Rennie (1999) state, nonetheless, that “some form of widely-recognized evaluative guidelines for qualitative research are necessary in order to win wider recognition and acceptability for qualitative approaches” (p. 225). The following criteria, suggested by Loh (2013) were selected as being appropriate for establishing trustworthiness in my study with military caregivers.

Member checking. According to Creswell (2009), “the final report or specific description of themes” (p. 191) is returned to the participant, where the opportunity is given to provide or deepen story context or suggest alternative understandings. This was accomplished through the vignettes, which each participant read, commented upon, and approved.

Peer validation. As a subset of member checking, this was provided by another PHDLIC candidate engaged in similar narrative inquiry research, thereby having the capacity to “provide . . . corroboration with regard to the interpretation of the data” (Loh, 2013, p. 6) I collected and analyzed. As Riessman (2008) reminds us, “a narrative is not simply a factual report of events, but instead one articulation told from a point of view that seeks to persuade others to see the events in a single way” (p. 187). Member checking controlled for bias.

Triangulation of data sources. This provided an opportunity to engage in repeated listenings and readings of taped interviews. This verified internal consistency, which Atkinson (2002) describes as “a measure to ascertain that what a participant says in one part of the narrative should not contradict what he or she says in another part” (p. 134). However, care was taken that the participant’s meaning was held, not so much as fact, but in the spirit in which it was meant. Additionally, two methods of analyses were used for this study, which triangulated the outcome more deeply.

Verisimilitude. This is a “criterion for a good literary study, in which the writing is clear, engaging and full of unexpected ideas. The story and findings become believable and realistic, accurately reflecting all the complexities that exist in real life. The best qualitative studies engage the reader” (Creswell, 2013, p. 54). In other words, trustworthiness is found in reading something that is believable or that “rings true” to a reader. Loh (2013) goes back to member checking and peer validation as two primary ways to ensure that verisimilitude is established in a narrative study. Contact with the Fellows was open between us and great care was taken that each participant’s narrative was represented with the highest level of care and authenticity as was possible. I felt protective of the treasure of each story.

To expand upon trustworthiness, Ms. Lorie Van Tilburg, LCSW, Founder of the Southern Caregiver Resource Center and Managing Director of Operation Family Caregiver, graciously offered her time to review chapter four of this study as a way of fact checking and verifying that the way I had interpreted the Fellows’ narratives was consistent with her experience of 30 years in the professional field of caregiving.

Utility. In this, the usefulness or relevance of a study is determined. This is what Riessman (2008) considers “the ultimate test”—does a piece of narrative research become a

basis for others' work (p. 193)? Can it be a contribution to a particular group of people? In 2014, the Elizabeth Dole Foundation commissioned a two-year RAND study on the military caregiver population. In a letter addressed to me from Steve Schwab, the Foundation's Executive Director, he stated, "One of the key takeaways of this [RAND] study was that there are many research gaps yet to be filled, which makes investigations like yours so critical" (personal email communication, October 26, 2016).

Thick description. This also contributed to utility when detailed contextual descriptions were provided in sufficient detail, which allowed for a transference of conclusions to other situations, people, settings, or times. Once again, this allowed for that holistic picture to emerge as an authentic representation of all military caregivers. Response to trauma is universal and there is not one of us who would not have similar reactions when faced with such a tragedy. The military caregivers spoke for us all.

All of these criteria were addressed and integrated into my research study.

Ethical Considerations

As a licensed, credentialed professional in the healthcare field bound by professional codes of ethics in both Speech-Language Pathology and Clinical Social Work, I continued to hold myself to both professions' ethical principles. Specifically, these broad principles are based on the core values of informed consent, service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence.

Therefore, I was very sensitive in my questioning and paid close attention to verbal changes in the participants that may have signaled difficulty with the interview. Clandinin and Murphy (2007) remind us, "Lieblich urges narrative inquirers to move beyond the institutional narrative of 'do no harm' by learning an attitude of empathic listening by not being judgmental,

and by suspending their disbelief as they attend to participants' stories" (p. 647). Additionally, the opportunity for each participant to read and comment upon her own vignette was a useful tool to eliminate any potential discomfort and gave the participant full and equal responsibility and power in the final decision-making of the co-constructed story. No triggers were encountered during the interviews based on the conversations and stories the participants were sharing and creating. However, as a licensed and trained professional in Clinical Social Work, I felt comfortable being with emotional upset and would have suspended my interview at any time should this have occurred.

Reflecting back on my conversations with the Dole Fellows, I was struck by their magnanimous generosity and transparency as they shared their stories about their lives and hardships. There was no sense of needing to perfect themselves or being anyone other than who they were. Their stories were real and raw. Without any pretense, each spoke her truth with dignity and grace. It was simultaneously refreshing and shattering.

Narratives and Analyses

Why do you stay?
 A question slaps me across the face
 You don't get to ask
 I do
 Where have all the loyal people gone?
 Who else keep promises?
 I love him (Comeau, 2014, p. 38) Reprinted with permission

The purpose of this study was to explore the lived experiences of women, vetted and appointed to the Elizabeth Dole Military Caregiving Fellows Program, who are living with and caring for their wounded, ill, or injured post-9/11 combat veteran husbands. In an attempt to understand more deeply the evolutionary processes caregivers go through following the traumatic fracturing of a life, 14 Elizabeth Dole Fellows were invited to tell their stories. On behalf of the Dole Foundation, they represented 14 different states across the nation.

The opening question to the 14 women was, “Can you tell me the story of when you first realized you had become a caregiver to your husband?” Each participant provided rich detail and background information that advanced her story to the point where answering my opening question brought her up to her present circumstances.

Two types of analyses were used for this study—plot analysis of the storyline and thematic analysis of the narrative. Since a singular method of analysis can never illuminate an entire phenomenon, it was hoped by using a method of triangulation that incorporated both plot analysis as well as thematic analysis, a deeper understanding of the caregivers' experiences would be produced. As a result, plot analysis allowed the deeper structural flow of each story to be revealed and thematic analysis uncovered the themes and subthemes, thereby providing texture and emotional tenor to the narratives.

As each woman progressed in her storytelling, the themes that arose across all participants' stories were interwoven throughout the plot analysis to keep the meaning-making and feelings of each woman connected. Moving dynamically, matching the flow of the story line, these themes deepened the understanding and sense-making each woman expressed at the various stages of her evolution, providing a continuous, thematic road map of her journey that spanned from three to thirteen years. Within each topical theme were subthemes that added to the depth and substance of each woman's progression in relationship to her husband and in understanding herself as his caregiver. Subthemes emerged from the detours, perspectives, and challenges the women faced.

In this chapter, I describe the findings of the plot analysis and integrate the thematic analysis onto the structural elements of the plot. Short vignettes condensed from the transcripts of each woman's story and excerpts from the interview transcripts are included to illustrate the interpretive meaning of the analyses. Agreed upon pseudonyms for the participant and her husband are used throughout.

Overview of Plot and Thematic Analyses

Using Daiute's (2014) plot analysis as a guide (p. 139), 14 individual vignettes, condensed from the initial interview transcripts, were written and organized along the continuous plot elements that supported the form and movement of each story. The eight plot line elements consisted of the character(s), the setting, initiating action(s), complicating action(s), the high point, resolution strategy(s), ending, and the coda. These eight elements represented the scaffolding of the stories' forward-moving action. Embedded within this action are the corresponding themes and their subthemes that enriched and embellished each plot element.

The prelude is presented as a general summary to orient the reader to the women and is not part of the storyline. Plot element 1, the *character*, and plot element 2, the *setting*, are the same in each narrative and therefore were not used in the analysis, although are summarized to give the reader a full rendering. All characters are the Elizabeth Dole Fellows who spoke in first person narrative, and all settings began in the home.

Table 4.1 is presented as a grand analysis to organize the remainder of this chapter by showing each advancing plot element and the related themes and subthemes. The description of action in each plot element in relation to the themes will be discussed in the next section with accompanying tables.

Table 4.1

Plot and Thematic Grand Analyses

Plot Element 1	<i>The Characters</i>	All were Elizabeth Dole Fellows and first-person narrators
Plot Element 2	<i>The Setting</i>	The stories were told from the setting of the women's home, but moved between inside and outside
Plot Element 3	<i>Initiating Action</i>	The motivating action in the plot or initial trouble expressed in the narratives
	Topical Theme 1	Hope
	<i>Subthemes</i>	If only Belief in the system
Plot Element 4	<i>Complicating Action</i>	Continuation of the actions that build from the initial trouble or initiating action
	Topical Theme 2	Unraveling
Plot Element 5	<i>High Point</i>	The climax or pivotal conflict of the narrative
	Topical Theme 3	Disillusionment
	<i>Subthemes</i>	Stress Failure/Frustration Shame Grief and Loss Depression Anger Isolation Leaving
Plot Element 6	<i>Resolution Strategy(s)</i>	The attempts used to resolve the main trouble or problem
	Topical Theme 4	The Turn
	<i>Subthemes</i>	Children Finances Acknowledging role as caregiver I'm not the only one Letting go of control/Choice Flexibility Ending blame
Plot Element 7	<i>The Ending</i>	A settling of the main plot conflict without the need to resolve it
	Topical Theme 5	The Shift
	<i>Subthemes</i>	Accountability Clarity Advocating
Plot Element 8	<i>The Coda</i>	The reflection on the entire narrative, the moral of the story, or transformation realized
	Topical Theme 6	Inspired Action
	<i>Subtheme</i>	The Elizabeth Dole Foundation

Stories, Plots, and Themes

The narratives of these women follow a common trajectory of feeling, hope, and action. In this section I present each of the eight elements of the storyline in conjunction with those themes that offer greater understanding of the emotional place that occupied the women as their stories unfolded. I selected the story vignettes to wholly honor their lived experiences, and excerpts from their transcripts that best illustrated the themes from each part of their stories.

Prelude. Each woman, ranging from a present day age decade from her 30s to her 60s, was in a committed marriage to the man to whom she was giving care, and all have children. Thirteen veterans incurred illnesses, injuries, or wounds as a result of their involvement in a post-9/11 war deployment. One veteran was injured stateside during this time and had had no deployments. Of the 14 women, four were married during pre-9/11 peacetime, two of whom experienced multiple deployments throughout their husband's military careers, and one was a retired military veteran herself. Prior to their husbands' illnesses, injuries, or wounds, their lives were a typical representation of military life. One woman summarized her life as saying, "I was 16 when I became a [military] wife. Everybody should be a [military] wife first because they are gone seven to nine months at a time . . . So you learn to be your own individual person and you have to learn to handle your household."

The remaining 10 women married during post-9/11 military war conflicts in Iraq or Afghanistan where the deployments were longer, ranging from six to 18 months. Two had experienced very little time with their husbands stateside before their deployments overseas. For six of the 14 women, this was a second marriage, where the growing families had become blended over time. By the end of the narratives, each woman had uniquely expressed being

proud of her husband, supportive of his efforts, and grateful for his service to our country. All marriages remain intact.

Character as the first plot element. The Dole Fellow was the main character and first-person narrator, eight of whom were active Fellows and the remaining six were in an alumni status. Their husbands represented the Army, Navy, Marines, Air Force, and the Army National Guard, and each had served our country honorably. Although as a group the women differed in age, education, and life experiences, they were united in their commonality through a devastating, traumatic event that forced a turn in their lives they never could have foreseen.

Quotation marks indicate direct statements from each, and anything written outside of a quotation mark was my own way of advancing the story or final narrative summary. All excerpts used to enhance the thematic analysis are direct quotes from the women's narratives and no interpretation was made by me.

Setting as the second plot element. Each story began exclusively from the setting of the woman's home, or what Bruner (1986) refers to as the "psychic geography" (p. 703). The home is an inside, private place. It is considered an intimate, safe haven that is predictable. Outside, the world is challenging and unknown, embodying metaphors of risk and danger. However, it became clear that the home was not safe for the women at some point in their journeys. The narratives moved between inside and outside, friends and strangers, lost relations and new connections.

Initiating Action as the third plot element. For most of the caregivers, the *initiating action*, or what is referred to as the problem or the action that motivates the plot, occurred within the refuge of the home, throwing into relief how fragile this space had become. There were several possible homecoming scenarios that were true for the veterans, such as coming home

with visible injuries, with a visible illness, or with no visible injuries. The veteran's condition upon final deployment home played a significant role in how quickly the trouble was expressed in the initiating action.

The story of Tara and Chief is presented as an example of one husband's having been discharged home with no visible injuries and the shocking contrast of a "devastating" action against the backdrop of the serenity of the home. This section in the vignette is drawn to the reader's attention by italicized text.

Tara reflected back to November 2006, "My husband was devastated when he processed out [of the military] . . . [because] when you get sick or injured there's no big hoopla for you. There's no big 'Wow, you did a great job and I know you're injured now but you still deserve recognition.' And whether it's some kind of a ceremony, a party, a retirement, honors, things like that, there is nothing. Nothing. And that hurt him. It was almost like, you've failed. Well, [he] didn't fail. [He was] injured protecting the country . . . it's such a slap in the face. It really is. You need rites of passage. It's all about rites of passage in our country and our world. There is [none] for that wounded warrior."

"That first month after Chief's medical discharge . . . hit him psychologically and things started going downhill. When he was on active duty, I didn't see it because he was still very active. Physically he was deteriorating but he was handling it psychologically. But then you-know-what broke loose during that [first] month that he was sitting home and I was at work and doing my volunteering. I'd go home and there he was just sitting there."

"Between the pain, the pain medication, and the drinking, Chief thought he [was handling] it." But he wasn't.

“The day that I came home from my job as a teacher and I saw my husband sitting at the kitchen table with two bottles of pills and his eyes were all red [was the day I identified as a military caregiver]. He had been drinking and there were the pills. I needed at that point to take care of a serious issue that was devastating to me and to him. I needed to put on a new hat and identify in a new position. And that’s when I called the VA to find out what to do. It took hours but I finally ended up bringing him to the psych ward, where he [stayed] the first couple of weeks.” But Tara could not rest there. She had professional accountabilities to manage and maintain. “In my role as a teacher, I had to go back to work the next day and I did not want to tell anyone. Part of me was ashamed and the other part was, as a teacher, you need to perform. I didn’t want to start crying in front of my friends, and peers, and colleagues, and then have to go into a classroom and give a lesson . . . so I held it inside.”

“But after he got help, which was number one, that’s when I opened up for support and the principal at my school offered me a volunteer position for Chief, and that was a real big highlight” for his psychological well-being. “That’s when I saw the increase in my husband’s life satisfaction. He had gotten the help for the possible suicide attempt and he had a purpose in life. [And even though] he wasn’t as active physically because of his physical problems, psychologically he seemed to improve.”

“Actually, I had to take early retirement because . . . I didn’t want him to drop again. I had plans; I was going to get promoted to the position that was my overall vocational goal . . . but I had to look at [that] goal versus my husband’s health. Well, there’s no choice there. It was an easy decision. And yet, really, sometimes I think, gee, I wish. But I wish that he was healthy [so] I could have done that.”

“When I go somewhere for the Dole Foundation, I get excited and he wants to come. And that’s where I filled my need to be productive.”

Table 4.2 lists the various medical statuses the combat veteran presented during this early phase on the storyline journey. The degree to which the medical or cognitive condition presented itself within the veteran often dictated the type of movement seen in the story. Brief comments have been taken from the transcripts.

Table 4.2

Initiating Action: The Third Plot Line Element

Home with visible injuries	"severe burns to hands, face, chest" "shot in face by sniper with 40% jaw injury" "leg fractured in training accident, then refractured his leg again"
Home with visible illness	"returned with persistent cough, fevers, cold chills, Iraqi crud"
Home after lengthy deployment with no visible injuries	"excited" "honeymoon phase" "he came home and it was craziness" "had burn pit flashback while grilling hamburgers" "he was so depressed and moody; he cried a lot"

Hope as a topical theme. Located within initiating action, is the topical theme of *hope*. When things are so far outside of one’s experience, it is natural they go unrecognized or unacknowledged. There is no preparation or articulation for catastrophic trauma. These caregivers were now fighting the war on the home front as their husbands had fought on the battlefield. The more unspeakable the situation, the stronger the hope that the situation would somehow get better. For those of us living outside the traumatic experience, although hope can look to the outsider like a denial of reality, it is, more importantly, a critical way of coping that must be played out over the course of a very personal timeline.

When [my husband] was hospitalized in 2009 with a mental breakdown and homicidal plan [to kill his boss], I thought he was going to go back to work. We both thought that. We both thought in a couple of weeks he was going to end up going back to work. I mean, even in that moment I was like okay, he needs to take that time off, a few weeks and he is obviously—I mean, of course he is going to go back to work.

Within initiating action as the third plot element, the story of Ann and Ryan is presented as a compelling example to illustrate the first topical theme of hope and how each individual journey must be traveled in its own way, in its own time. For Ann, her unspoken reality expressed itself through her body and behaviors well before she was able to articulate what both she and her husband were facing. Yet, the trajectory of her eight-year narrative led to profound truths and honest expressions of her life. The reader's attention is drawn to a husband's final deployment home with visible injuries, with subsequent multiple invisible injuries diagnosed, and how Ann's hope was expressed in a very personal and unique way. For ease of reference, the condition of hope as Ann personally experienced it is italicized in the vignette.

Ann's husband, Ryan, came home from Iraq in 2008. "He had been shot in the face by a sniper. The bullet grazed the nerve bundle in his chin and it blew out [through] his neck, shattering 40% of his jaw . . . [and twisting] his spine." Over time, Ryan would also be diagnosed with TBI, PTSD and tinnitus.

Upon Ryan's return home, Ann, who worked full time, said, "*I didn't realize for almost 4 years that I was already in a caregiver role.* During this time, he was forgetting to take any one of his 29 medications, was missing appointments, wasn't showering, was getting kicked out of therapy programs, and he wasn't eating because he wouldn't cook for himself, fearing he would forget what he was doing and burn the house down.

Meanwhile, *I had gone from being [my company's] very best employee to being on the*

brink of getting fired. I was forgetting things, was late for work, and was tired and short-tempered.”

“One day I was getting ready for work and Ryan was lying in bed shaking. I automatically knew why and asked him what medication he had not been taking. When he told me he had been out of his nerve medication for the past 3 days, that’s when I knew we had a problem . . . on top of the problems he was experiencing that I had not noticed, I was struggling myself in my job.” Ann and Ryan’s individual struggles had now become one collective problem.

Ann’s boss suggested she take an 18-week family medical leave. “I didn’t want to. It took me a couple of weeks to finally throw in the towel . . . I ended up not returning. And it’s really been a [financial] struggle for us ever since.” Adding to this, Ann talks about the people who are closest understanding the least and the “harsh judgment . . . that comes from [our] own families,” implying that Ryan “didn’t have the things wrong with him that he said he did . . . that he was abusing his injury [to qualify for couple’s retreats] or that he was not grieving the right way. It’s very isolating because they don’t understand this new person who has come home. They don’t understand what we go through just to be able to live every day.”

“Still to this day, when Ryan wakes up, the very first thought that goes through his mind is, “Why did I wake up?” Every single day. He’s in that much pain. But then he sees me and that changes [even though] I know he struggles with [suicidal thoughts] every day of his life. I think we’re in a better place now than we were before. But we can always go back there. We always can go back. It’s pretty much a day at a time [and] it takes a lot of faith [and] patience . . . [and] planning in detail. We have a hallway that

we call our information hallway . . . I've got a dry-erase calendar, bulletin board, chalk board, a chore chart, and that pretty much is the heart of our lives. You have to be very structured, but you have to be ready to change at a moment's notice . . . Yeah, to try to explain to somebody about trying to be very structured, but yet be flexible at the same time, is very confusing."

Ann's reminder is strong. "I'm 24/7. It's like you're an on-call nurse every single day of your life with no days off. And I realize that if they actually compensated caregivers the way that [we] should be compensated, we would run this country broke."

If Only as a subtheme of hope. This is a significant subtheme of revolving hope, where *if only* the right conditions, professionals, or group of people were met, if only the right resources found, life would be different, better. In the beginning of this evolution, this search was crucial, often leading to important information and at least a temporary sense of comfort.

I was trying to fix him, fix it. I felt like if I did enough, if I got [him] to enough doctor's appointments, if I found the right specialist, then maybe . . .

I was constantly on the Internet searching for other caregivers, searching for people that had husbands that were having stuff the same as mine, just trying to find people to talk to, to find out what they were doing.

Belief in the system as a subtheme of hope. The medical system is a critical entity in the lives of all military veterans and their wives. For some, their state systems worked in appropriate concert with the veteran's needs. Others did not have that experience, despite all caregivers wanting to *believe in the system*, hoping and trusting it would adequately care for their husbands' medical problems.

And you know, I thought military medicine, that's the best. Of course they know what they are talking about. You know? So it's like [they made] everything [sound like it was] hunky dory.

When they're at the mercy of the VA, they [the veterans] just have to pretty much just go with what they're told, whether it's right or wrong, they have to take it. And so, when they tell them they have to wait six months to get an appointment, they say, "Okay, what else am I [supposed] to do?"

The story of Betty and Ed is presented as another example of an initiating action where the combat veteran returns home with a visible injury, later to be diagnosed with multiple invisible injuries. Her story is an excellent example of the belief she and Ed placed into the hands of the medical system, what happened as a result, and the wisdom Betty gained as she made her way through the next 10 years. Sections in her story that highlight the subtheme of *belief in the system* are italicized.

Betty and Ed. Ed's parachute free-fall training accident happened in 2006. Betty remembered, "He had a bad leg fracture and was knocked unconscious. Initially it was like, oh, you're ok . . . [but] then things got progressively worse." Rods were inserted into his leg but, several months later, he wound up re-fracturing his leg above and below where the rods had been placed. Several surgeries followed, but his wounds weren't healing. *The medical staff "wasn't taking what was going on seriously. They put him in a cast, just casted over open wounds. Twelve weeks later, they took the cast off and his leg pretty much looked like hamburger meat. The medical team responded by re-casting him with a window in the cast, expecting me to do my own wound care on Ed's leg and that's when I realized how serious this was.* The medical doctors actually looked at us in the face and said, 'He doesn't have an infection.' They never gave him antibiotics [for] an oozing wound that never healed."

A year later, the wound had still not healed and Betty was so stressed out that she demanded Ed rise above his "military mentality" and talk to his command. He went to his dive doctor and, upon seeing his leg, was immediately transferred to Walter Reed

Military Medical Center and was instantly diagnosed with a MRSA staph infection in his bone. Thirty surgeries were to follow. Around this time, Betty started noticing “a lot of mood changes, cognitive issues . . . and between all the surgeries and stress, he was mentally and physically exhausted. At that point, I had already become a full-time caregiver and, [with also managing 4 girls], was on my way to a nervous breakdown that year . . . I thought that 2007 was going to be my year.” Fortunately, it wasn’t. In February 2010, Ed had his leg amputated, and Betty remembers sitting in the OR Waiting Room for seven hours by herself, with just her thoughts and her emotions. No staff came. “It was a really hard thing.”

Betty’s most difficult realization from this experience was that she, as Ed’s caregiver, was never approached as having anything of value to offer to the medical staff and was often blatantly ignored. I would ask them, “Sir, why does it look like this? Why are we having to do this?” “Oh, it’s fine,” they’d say. Or, [they wouldn’t] even answer my question, or [would] get irritated [with me].

“You’re not listened to, even though you know the situation more than maybe the veteran himself. But [we’re the ones] paying attention.” In 2010, Ed “was finally diagnosed with PTSD, TBI and chronic pain . . . just to carry on a conversation, his understanding, is a day-to-day challenge. Today, he is 100% disabled.”

Betty reflects, “If I could go back, I would have asked for help sooner [because] I can’t do this by myself for an eternity and carry all the weight of the emotional and physical stress that being a caregiver requires. This is a life-long commitment [and that’s] a lot to deal with. When someone has PTSD or a TBI, it’s common across the board—they’re not being assholes. It’s their whole body system that’s failing.”

“We have times where we’re crying together; but we’re still able to laugh together, too. Even though there are so many things, and it would be easy to walk away, I choose not to do the easy thing. I want to make it work. I don’t want to leave him.”

Complicating Action as the fourth plot element. Building from the initiating action, the story’s plot line progresses into the *complicating action*, or the story’s motivation. Due to the perniciousness of invisible injuries in particular, and how complications ebb and flow, this element on the plot line underscores how multiple crises may continuously arise over the years.

The story of Olivia and Jack illustrates the cyclical nature of the invisible wounds of war and how a story’s motivation continues, yet changes over time. The complicating actions in this story are italicized for the reader.

Olivia and Jack. Olivia is a vivacious, energetic, talkative young woman with two graduate degrees. Highly resourceful and resilient, she is no-nonsense when confronting any crisis.

Olivia was “very excited” when Jack came home in September 2007 from a 15-month deployment and they “got pregnant right away.” But by December, “it was apparent that there was a real problem [that] wasn’t part of normal readjustment and reintegration.” Jack was different, “detached from his surroundings,” withdrawn, separated. Olivia explained, “If he wasn’t in bed with the lights off, he was on the couch in the fetal position with his computer, the TV, and CD’s going but he wasn’t really paying attention to any of them.”

There was a “defining moment” in March 2008 when Olivia, now 6 months pregnant, had to rush Jack to their military hospital in the middle of the night, fearing he was going into anaphylactic shock as the result of an allergic reaction from his many

medications. “He was breathing so heavy that all the windows in the car fogged up. He was slamming his head against the window. I pulled up to the ER and they came and got him. When I finally entered his room, he was strapped to a bed, slamming his head . . . They were injecting things into him and he was shouting . . . it was my idea of what every horror movie would look like. Everything shifted from that moment” for Olivia, but even then, it would be another three years before she thought of herself as more than “an overwhelmed, busy spouse who was trying to do everything.”

By June 2008, Jack “had deteriorated to the point where he couldn’t remember anything,” including that Olivia was getting ready to give birth to their son. By the time the baby came home, Jack’s condition “was just awful . . . the baby would cry and Jack would melt down. He began hiding under the bed, stabbing knives into Goldfish bags.”

Jack was medically retired from service for severe post-traumatic stress disorder, and was later diagnosed with traumatic brain injury, chronic pain, and significant mobility issues. Over the years, his challenges have shifted from panic attacks and screaming at people in public, to severe depression, suicide attempts, and declining physicality. “He’s no longer hiding under the bed, but he’s falling down the stairs. I don’t know if it’s better or worse. When we have a crisis, and it’s not rare, I don’t even have an emotional response [anymore]. I just automatically jump; I’ve got to get into action. I just do it.” When confronted with the depths of Jack’s needs, Olivia chose to hire a live-in caretaker, allowing her to keep working. This was a critical move that continues to support her emotional and psychological well-being to this day. As Olivia says, “I pay a lot of money for that live-in [caretaker] and it’s because I want to work. I

could have a lot of nice things if we didn't have her [laughter]." It is a compromise based on the reality of her circumstances.

Olivia concludes, "My marriage is not what it was, what I would like it to be, or what I ever dreamed as a little girl that I would have. [But] my husband loves the hell out of me [and] I'm in it for the long haul whether it sucks or not. Truthfully, if I was going to leave, I could think of 800 times when that would have been a really good time to like, throw in the towel. I guess I have to believe the best is yet to come because I'd like to have that outlook in life. We get a lot of curve balls, but it's just function and maintain. People ask me how do you do it. I just do it . . . this is my life and this is what I'm doing. I definitely didn't choose this and neither did my husband . . . but I'm agreeing to stick it out and do what I can . . . to stay in this situation and make the best out of it. [I was a military brat]. I'm [a resilient and] very loyal person."

Table 4.3 lists the primary conditions that led to the movement into complicating action, the fourth element on the plot line, with individual supportive comments.

Table 4.3

Complicating Action(s). The Fourth Plot Line Element

Cognitive or emotional decline or disrupt:	"He was getting lost, forgetting, losing whole parts of the day." "He can't carry on a 30-something conversation anymore."
Affected brain function	"paranoia, insomnia, rage, extreme depression" "My husband had gone missing; he called police on himself; got himself arrested." "He forgets to eat, to shower, to change his clothes." "He had 3 more suicide attempts."
Flashbacks	"He snapped in the car; punched me; I lost my sight temporarily." "Driving home he yelled at me to get out of car; he was back in Iraq." "His eyes were all black and he wasn't there."

Unraveling as a topical theme. Located within the complicating action plot element is the topical theme of *unraveling*. Enough time has passed and now two facts are converging. There is a marked change in the combat veteran's ability to function, whether physically, emotionally, or communicatively. In some cases, flashbacks were experienced. On the other side, the women were beginning to realize the weight of what was beginning to be expected of them. Many were without any services or resources. One was on the verge of becoming homeless. Some women recognized how dire their situations were. Others did not recognize this as quickly, yet inherently understood demands on their lives were changing. At this stage of the story, many women could not define what these demands meant, as they had no history with these changes but they knew they could no longer project into the larger context of their futures with any predictability.

He was drinking a lot, stuttering a little bit. And so, I started noticing more of the nightmares and the problems at night time, so once the baby was born it became worse because then he was hypervigilant, and . . . he was just very angry . . . and I started noticing how he started getting depressed once the baby was born . . . he was just becoming depressed and just feeling kind of hopeless.

I didn't know what I needed to be doing.

We were just kind of trying to navigate it ourselves. He was self-medicating with alcohol. It was bad. It was really bad.

The High Point (Climax) as the fifth plot element. The stories now tipped into the *pivotal conflict or climax* of the narrative. At this point, there was no turning away in pretense, and attention to the situation was demanded. Being confronted in this way may give one the illusion of a handle, something that can be held or grasped, allowing for movement towards a concrete resolution, only to find a complex system of need below the physical surface.

For the wives, their emotions ranged from on-going stress to shame, grief, and loss. Several left their husbands temporarily, either as a way of "forcing" them into treatment, as a

safeguard against potential violence in the home, or as a way to model to their children the importance of boundaries.

Disillusionment as a topical theme. Located within the high point plot element is the topical theme of *disillusionment*. With the crumbling of the belief and hope that life was going to get better if only something more could be done or a better professional or different program could be found, what inevitably led to disillusionment were the difficult emotions that kept arising when it was acknowledged that the hope for the couple's future had begun to fracture, despite what the caregiver was doing.

Stress as a subtheme of disillusionment. The response to trauma is so intense that *stress* was a predictable response in the women, whether it was acknowledged initially or not. Many caregivers spoke of on-going stress in varying degrees, like a persistent backdrop in their lives. This sense of being overwhelmed was the result of the myriad emotions the caregivers experienced and continue to experience to this day.

and then I became very stressed out and I was almost like a victim of domestic violence. He never even touched me at all, but I would run to work and run back to the house and I wouldn't even stop at Burger King to get food because I needed to get to the house. It was [that kind of] stress that I was under and I put that on myself.

but I know that in my situation . . . that there's no way that I'm going to get away from stress, because if I don't have stress as a caregiver, I've got just other . . . things here in [my] daily life that can cause stress.

Frustration/Failure as a subtheme of disillusionment. Many wives spoke of their *frustration* with the hurtful messages they were receiving from the medical staff. Often feeling as if they were *failing* their husbands, many were too early in the process to trust themselves.

I don't think that I've felt like I had the support from the day that I was in that waiting room, when the military hospital was basically telling him there's nothing wrong.

What happened is we came back to [his VA] doctor and we told him what was going on. Gave him all the reports. Gave him everything, pictures, you name it. He says, "Oh, am I

Captain of this ship now?” Yes! He said that. It’s easier [for the doctors] just to say, “We don’t know what’s wrong with you. Here, take these drugs.”

Within the high point or climax as the fifth plot element, the story of Charlotte and Jonathan is presented to illustrate the initial frustration encountered within the medical system, the hurtful statements that were made, and the extraordinary way Charlotte dealt with “the dreaded” inconclusive medical diagnosis. The climax of the story and the subtheme of *frustration* are italicized for the reader.

Charlotte and Jonathan. What happened to the trash during the wars in Afghanistan and Iraq? It was all dumped into pits. Burn pits. Lithium batteries, tires, body parts, dead animals, medical waste, chemical drums, plastics, blood and clothes of the wounded, human waste, everything, all soaked in jet fuel and set on fire, creating an open-air dump spewing toxic smoke, gasses, and chemicals into the air our soldiers breathed, where they slept, ate, and worked. Like a 24/7 heavy fog, the smoke, different colors depending on what was burning that day, often rose to knee-deep levels. As early as 2004, soldiers were returning home with symptoms. This is where Jonathan’s story began.

Charlotte and Jonathan were high school sweethearts. “I was 14 and he was 16 when we met and we’ve been each other’s partners and soul mates since then. I was 16 when I became a military wife. We’ve always only known each other.” That was 38 years ago.

In 2004, Jonathan came home from his first tour of duty to Iraq and couldn’t shake the persistent fevers, coughing, cold chills, night sweats, and blood in his mucus—called Iraqi crud. But testing came back “inconclusive” and in 2007 he was released for another deployment to Iraq. But this time he told Charlotte, ‘I found blood on my face. I touch my face and keep finding blood.’ *As soon as he got home “I got him to a*

dermatologist and that's how it all began. He had skin cancer and they had to reconstruct the center of his face from the cancer." But then Jonathan began suffering from massive headaches, chronic fatigue, hearing loss, breathing difficulties, and lumps on his body that turned out to be tumors. *"The doctors told me he had PTSD. But I told them PTSD doesn't cause tumors, or coughing up blood. They told me my reaction was part of the problem. They said, 'It's wives like you that cause soldiers to commit suicide because you won't admit they have PTSD.' I never said that. I said he had tumors. [It took 7 more years] before Jonathan was finally diagnosed in 2011 at [a major university medical center] with constrictive bronchiolitis due to his service in Iraq. There was no other explanation for my husband's illness. His body is full of nothing but toxins and chemical exposure from the burn pits. His condition is terminal. Every time he breathes in, it's like breathing in a cactus."* And this is where Charlotte's story began.

"I am here to fight for every veteran and caregiver out there that is struggling because of the burn pits and the [illnesses they cause] that other people simply do not recognize. I am not here for anything else . . . I am fighting for awareness." Charlotte's quest became her cause. "I started with our state Senators, then Commissioners, the Congress . . . anybody who would listen. We met 9 other families and got together. We worked on a bill and what needed to be done. But it was one of my Senators who ran with it. He worked with my husband and me and we were able to get a bill through the Senate, through Congress. *Eventually our bill went on to President Obama's desk and in 2013, he signed our bill into law, creating The National Burn Pit Registry. And I know it takes thousands of veterans to get sick and die before those registries really get to working properly . . . but my husband was one of the first veterans recognized and able*

to be medically retired because of his illness. So I am his caregiver. I am his wife. I am his best friend, his partner, his confidant. He is my pain in the ass. You know what I'm saying? Do you understand? Like my husband says, there's no guarantee in life and there never has been. So we're gonna go with that. Just live every day as much as we can."

Table 4.4 is predominantly emotionally based. Although as the wives continue to move forward, their lives are circular and they talk about their cycle back into emotions, knowing they can always return to a more difficult day.

Table 4.4

High Point (Climax): The Fifth Plot Line Element

The Emotions Giving	"He had several more suicide attempts that followed."
Way to Crisis	"He was breaking down the door; he said he was going to kill me."
	"It's never going to get better."
	"I knew our lives were different from that point forward."
	"His first suicide attempt. As his wife, how could I not have known?"
	"I realized he could never be trusted in a doctor's appointment alone again."
	"That night my daughter saw everything and firm boundaries had to be drawn."
	"He saw his medical records calling him unfit for employment."
	"He found his purpose and I hit rock bottom."
	"I pick my battles; I don't want to light the fuse; I don't know what to expect sometimes."
	"I left him but I always did my caregiving duties."

In addition to the challenges trying to work the medical system, many caregivers spoke of this subtheme of frustration in describing their extended families and friends and how these support systems were failing them. As a result, many caregivers expressed their need to manage the communication in their relationships.

They talked a lot about him because they thought that he was just home because he was lazy and nobody knew how bad his seizures and his migraines and how bad his anxiety was and none of that. So we didn't get any support . . .

People would look at us and be, “Isn’t that what a wife is supposed to do?”

I don’t speak much with my biological family because they don’t understand why I choose to stay in a marriage, this marriage. “Nope, if you’re going to be with him, I can’t support you, I can’t support you being with him.”

A difficult part of all of this was trying to get other people to understand . . . Some people think, “Oh, you know, well you’ve got it made, because you’re home,” or, “You’re not out working like 50–60 hours a week.”

Shame as a subtheme of disillusionment. *Shame* and embarrassment were often expressed as responses to the caregivers’ husbands’ behaviors that were seen as or believed to be less than socially acceptable. The comparison made when recognizing differences in their lives versus their neighbor’s lives was an extreme reality for many caregivers.

The nightmares were at [their] highest. I would wake up. All the lights would be on and he would have a bible in his hand, crying hysterically . . . [or be] out in the street in his underwear with a gun in the middle of the night because he heard something . . . We didn’t have friends because of [his] behavior. It was really sad. That’s when I began to feel like the shame and really, really alone.

And I remember sitting there [in the group] and telling them [this recent story about my husband] and feeling so embarrassed and ashamed, and then . . . one of them started laughing and I was ready to punch her in the face because I was so angry that she was laughing at me and I was like, “Why are you laughing?” And she was just, “Girl, what are you ashamed of? We’ve all been there.”

Grief and Loss as a subtheme of disillusionment. These states were frequently articulated. However, when a wife found herself resting too long in a space of *grief or loss*, her antidote was to move into some type of physical action or movement. For many, the experience of grief and loss continues to move in and out of their daily experiences.

If I think about it, it makes me incredibly sad because . . . what I was feeling was grief and loss . . . knowing that my future when I married [him] is not going to be what I thought it was going to be, even what [he] thought it was going to be . . . But, I can’t think about it because I can’t live in that space . . . I get into action.

I am mourning who he used to be because he is never going to be that person again . . . I would give anything to have my husband back, the man that I married, but . . .

It's not the marriage either one of us would have chosen.

Depression as a subtheme of disillusionment. This feeling was also expressed and acknowledged as deep sadness. The story of Alicia and Dennis is a poignant story of one young woman's internal battle with all of her husband's new behaviors and how she has begun to learn a most important lesson towards her own self-care. The story is presented within the fifth plot element of high point or climax and references depression as a subtheme of disillusionment at this point on the storyline. This continues to cycle in her life to this day. References to both plot and subtheme are italicized for the reader.

Alicia and Dennis. Alicia's husband, Dennis, suffered five separate IED-related concussions during his numerous deployments to Iraq. This ultimately led to diagnoses of TBI, severe PTSD, vasovagal syncope, and seizures. "He stumbles, passes out, gets disoriented, and things like that. He has not worked outside the home since September 2011, following his first suicide attempt."

For Alicia, 2011 was a pivotal year. Earlier in the year, both she and Dennis were working full time. But he started "having distress at work, struggling with getting out of bed and making it to work on time . . . and then he started becoming very angry, very agitated . . . and having thoughts of shooting people in the head." Finally, "one night he snapped in the car and started screaming, 'I'm responsible to make sure you get home to your mama and I'll be damned if it's going to be in a box! Are you trying to get yourself killed!?' He was completely not with me and at the time, I got angry because he just kept screaming and hollering and I was becoming scared . . . *The next thing I know, my whole world's spinning. He had punched me while I was driving. Four broken bones and I lost my sight . . . I was barely holding onto consciousness.* But finally it kind of smoothed out

and I started seeing again. The passenger door was open and he was nowhere to be found.” Alicia finally found him, marching up the street. The only way she got him back in the car was to order him in. And when she finally got him home, “that’s when . . . my brain is trying to process, ok, what in the hell just happened? Where is he? Something is really wrong . . . I was scared, did not know who to call or where to turn to, but I knew jail was not the place he needed to be.” She planned on getting a few things and getting out, but when she saw Dennis on the sofa “with a gun on his chest, then pulling it to his head, [she thought] Oh my God, he’s going to kill himself.” So I sat in the bedroom and watched him [until] he fell asleep with the gun on his chest. The next day, I finally came out and he looked at me and said, ‘Good God, what the hell happened to you?’ I looked at him and said, ‘Don’t you remember? You did this.’ And when I told him that, the color drained from his face and he passed out. Later, when he came to, he said, ‘I don’t think I’ll ever be able to forgive myself or live with myself after what happened. I was trained to eradicate threats. I am a threat and I need to be eradicated.’ And that scared [me].” But there was something deeper going on. He had another three suicide attempts “and I [finally had to drop] to part time work and then it wasn’t but a few months later, more distressing text messages, memory loss, it just became evident that I would not be able to work outside the home and ensure his wellbeing.”

“I sink into depression, I’m not going to lie. It feels like you’re on a sinking ship which is why it’s very important for me to return to work, get out of the house . . . I often feel like I’m drowning [but] you can’t allow yourself to sink; you can’t be of any help to anyone if you can’t help yourself . . . but I realize I can only do so much . . . and [it’s not in my control]. If he ever becomes truly committed to taking his life, there’s going to be

nothing I can do about it . . . I cannot physically overpower him . . . *I feel like I'm sitting on the edge of a seat waiting for something to happen . . . it's like being in a perpetual state limbo, of not knowing. You can't rest too comfortable in the moment. You have to be ready, like a firecracker jumping around you. You've got to watch it and see where it's going, pay attention, and be ready to move when it gets near your feet.*"

"I've literally put my whole life, my personal dreams, my goals, I've put it all on hold, and if something were to happen to my husband tomorrow, how will I take care of myself and my [17-year-old] son? That's been the reality . . . I have to prepare for a life after my husband . . . Now I'm focusing on controlling my own wellbeing and letting go of controlling other things I can't control. Let me get in touch with my own self first."

Anger as a subtheme of disillusionment. In the narratives, degrees of *anger* surfaced from extreme anger to extended periods of upset. In this analysis, *anger* is presented as the last emotion. Emotionally, it represents a necessary expression, allowing the caregiver to begin to move outside of herself in another step forward.

And I kind of went down for a couple of days. I didn't want to talk to anybody. I didn't answer my phone. I wasn't on Facebook, didn't answer e-mails, and I just kind of realized that, "Oh, my gosh, this is not the person I want to be, like why am I so angry?" I needed to focus on more than just my anger.

My son sees I'm starting to get really upset and goes, "Seriously, seriously, can we please have just one normal day?"

I had come home and things were just not the way I expected them or thought they should be, and I just lost my mind. I was mad, and angry, and it just continued . . . and [then] somebody said to me, "What is such the big deal? You've just—you've got to stop being so mad at just whatever you're so mad at."

Isolation as a subtheme of disillusionment. *Isolating* was a common strategy used by many of the wives to hide themselves, their feelings or their circumstances. Some became very adept at keeping others at bay, including family and friends.

I completely segregated myself. To this day I still isolate a lot, and so I used a lot of what was going on with [my husband] as an excuse.

It was very, very difficult. We were very much alone and isolated as a family.

I isolated a lot. I accommodated for all of the situations. I had a way . . . of getting away with [how] we were living . . . I never really needed to interact with people . . . I went from having all these friends [to] people who saw me on the street [and thought I was on vacation] because they [hadn't seen me and] didn't know I'd been back [for 5 years].

Leaving as a subtheme of disillusionment. Several caregivers separated from their husbands temporarily either because lines had been crossed, examples needed to be set for the children, or in one instance, *leaving* was the only way this caregiver could get her husband to agree to accept treatment.

I told him, "I know this isn't you, this is injury and I love you. But [your daughter] and I will no longer be around you, period, if you've had another drink. I won't put myself at risk anymore whether it's to take care of you or not." And that was the start of 5 months of going back and forth between a hotel and my house.

He was leery because the military . . . still has this stigma to ask for help. But I knew if I said I will leave if you don't get help, he would get help. And he did. I had to leave him in order for him to get help.

There was a restraining order against him. But I still [did] my caregiving role . . . I only lived a block and a half away. He was actually court ordered to be in a mental hospital for 17 days because it was really the only way I could get him to get on any type of medication and get him back because he wasn't himself in any way. And I was still very unsure when I went home that I was willing to give it a chance.

The story of Beth and Matt is illustrative of many subthemes discussed so far in the topical thematic area of disillusionment, but is also a beautiful example of a high point on the storyline, when one woman's perception of the effects of her husband's behavior on their daughter could not be tolerated, causing the need for restructuring her life and reimagining her future. For ease of reading, the high point of the fifth plot element in this story is italicized.

Beth and Matt. "Matt and I were only married 2 weeks before he deployed to Afghanistan for 13 months . . . and when he came home in 2009, for that first year it was craziness.

Beth remembered thinking, “What did I do? This my marriage and my husband is just a terrible person.” During that first year home, “he had gone into Walter Reed and was in the Warrior Transition Unit for severe PTSD, and was eventually diagnosed with TBI. At the end of 2010, [the military] medically retired him because he wasn’t fit for service, although his treatment wasn’t finished. So in one swoop the week before Christmas, [our] little girl, Matt, and I lost everything. When he brought those orders home, it meant he was losing his job, our income, and our [base] housing. [The military was putting] us out; we had nothing, no savings, no possibility. There had been civilian contracting companies interested in Matt, but he couldn’t even handle showing up for a doctor’s appointment, much less hold a job where he’d need a security clearance. We would have been homeless had we not been very blessed that I found Operation Homefront Village as transitional living.

But after the family transitioned out seven months later, following Matt’s treatment for PTSD, “The next 3 years were terrible. We were navigating it ourselves. He was self-medicating with alcohol and it was bad. It was really bad. *One night he thought he was [back] in Afghanistan and I couldn’t calm him down. He had gotten so angry and [it was] so bad that I remember putting furniture in front of the door to our bedroom. I could hear him and the door breaking and I remember putting my daughter in the shower and closing the curtain . . . I didn’t want her to see. The police came and they tazed him, and my daughter still remembers that because he tried to get them to shoot him. And then there was another incident and some lines were crossed or at least blurred. At that point I had to [stay] safe and set a fair example for my daughter. I had to set some very firm boundaries. I told him his daughter and I wouldn’t be around him*

if he had another drink. Period . . . that I wouldn't put myself at risk anymore whether it was to take care [of him] or not . . . and that was the point that I [started to feel] some sense of control."

"I can't control his injury and I can't control the choices he makes. I can only control the things that I do [for me] and for my daughter. So that was the change, realizing that I do have some control of the situation, not over him or his injuries, but that I'm not helpless in this situation.

"I've accepted it versus in the beginning where I was trying to fix him, fix it. I felt like if I did enough, if I got [him] to enough doctor's appointments, if I found the right specialist, then, maybe . . . but I've accepted that this could very well be what it is and what we do from here forward . . . is to try to find a balance."

Resolution Strategy(s) as the sixth plot element. Continuing along the plot line from the high point, attempts to resolve crises varied as *resolution strategies* were considered and put into place, sometimes for the moment, other times for the longer term. Beyond the need to manage their husbands appropriately with strategies for care, a significant motivation that moved the caregivers into the resolution stage on the plot line was either their children or their finances. Both were almost equally reported as being crucial grounding elements that focused the caregiver's attention on their hard realities. From here, they began to talk about the needs of their children or their need to understand their finances much more specifically to prepare for the future.

The story of Angela and Ben is presented as an excellent example of the hard reality of the awareness around *finances*. In this vignette, Angela speaks of the fear that arose when she inevitably confronted her financial future, making this a critical juncture in her turning point.

Areas specific to the sixth plot element of strategy(s) and the subtheme of finances are italicized to mark them in the context of the story.

Angela and Ben. Angela recalled, “Ben and I married 4 months after we met; a month or two after he returned from Iraq in 2005. We were young; only 26 years old [and for those 4 months] we were as inseparable as you could be. The moment I realized something was wrong was [after we had gotten married] and I had moved in with him on base. He turned into a completely different person. He was paranoid, had insomnia, had started having just crazy side effects from medications he was taking. He wasn’t stable emotionally and he was also dealing with harassment from his command and higher ups for receiving treatment for PTSD . . . and I remember thinking Oh my God, oh my God, what did I just do? What did I just get myself into?”

“In 2005, PTSD wasn’t a big deal and [the military] minimized it. Psych was like, oh, I think you’re fine; you’re good. And he was like, great, ok, they don’t want to give me treatment anymore. I was young, I was naïve, and I was a newlywed. And he was getting out.”

“[In 2006] we moved off base and Ben went right into a road construction job. Well, when he got out [of the military], that’s when the PTSD really, I mean, really showed itself. It was this rage, extreme depression. He would come home and go days without saying a word to me or the kids . . . screaming in public, road rage, holes in the wall. Every few weeks he would have a suicidal [thought] and the nightmares were at their highest. I would wake up. All the lights would be on in the house and he would have a bible in his hand, crying hysterically; or he would be out in the street in his underwear with a gun in the middle of the night because he heard something. We’d been

kicked out of restaurants. And that's when I began to feel really alone, the shame, and I realized how different we were from other people in our new community. That's what it was like for 3 years.

“In the summer of 2009, he [told] me that he had a plan to kill his boss and when he told me his getaway plan it really hit me and I had to compose myself. I went into the bedroom and called the VA Crisis Line, got him back in the system, and he was put on a 72-hour psychiatric hold, hospitalized, and from there was diagnosed with a TBI [from several blast wounds 5 years ago]. In 2010 he was diagnosed with a neurological visual impairment due to the TBI.”

“When he started having seizures, I could get no acknowledgment or support from the medical staff. I started a tedious documentation of Ben's seizure activity at home. It would take another 16 months before Ben was finally diagnosed with left temporal lobe epilepsy. And now we're prepping for brain surgery because his seizures have gotten so bad.”

“In 2016, I really started having the thought I have to prepare [for the future, and] it makes me incredibly sad. I am grieving knowing that my future when I married Ben is not going to be what I thought it would be, even what Ben thought it would be . . . [but] I need to take action. I have not been able to build on a career or to further my education because my life has been devoted to caring for Ben and our children. Because I am a family caregiver, I have not been able to pay into Social Security. So what would that do to me in the future? That scares me. [Caregivers] need [financial] security. We need to make sure caregivers are going to be taken care of, devoting [our] time to a loved one and not being able to pursue [our] own dreams and careers. I've learned

everything I can possibly learn about epilepsy, PTSD, TBI, visual impairment, fibromyalgia. Where's my degree? *We need to make sure we're going to be ok.* [As] Elizabeth Dole Fellows, we are very loyal. We are fighters. We are determined. We are resilient. There is no backing down. We are going to make sure our voices are heard.”

Table 4.5 summarizes various strategies implemented by the wives as they made their way through the ever-changing lives with their husbands.

Table 4.5

Resolution Strategy(s): The Sixth Plot Line Element

Reciprocity	"We take care of each other now"
	"I keep the stress on me and it's less stressful for our family"
Reaching out	"I've learned it's ok to ask for help"
	"I ask for help now"
Attitude	"I always find a way; I don't let myself get pushed down"
	"I asserted myself to get him to take care of his needs"
	"I choose my mood every day"
	"I persevere until I find a way"
	"I pick my battles"
Concrete Solutions	"I'm in it for the long haul"
	"The information hallway —it's the heart of our lives"
	"We don't live near our families"
	"With my Senator, we wrote a bill that was signed into law in 2013"
	"I work full time to pay for someone to take care of him"
Education	"I set firm boundaries for me and my daughter"
	"I have daily rituals of self-care"
	"I've learned everything I can possibly learn about everything"
	"I'm in school studying Criminal Justice to become a veteran's advocate"

The Turn as a topical theme. Within the sixth plot element of resolution strategy(s), this critical shift, or *turn*, that for most took several years, was the point where the caregiver began to trust herself and express her realizations with deeper wisdom and simplicity, yet often with more intensity as she looked to the future. This shift typically began in response to one of two powerful areas: *children* and *finances*. This evolution also marks the tipping point in the sixth

plot line from the story's high point or climax to the more concrete element of resolution strategies.

Children as a subtheme of the turn. The children were the caregivers' opportunity to see their reality for what it was. They recognized how important it was to set positive behavioral examples for their children. They also spoke about their children as not being raised as "normal" children and that the children needed support in ways that many of the women had not yet realized.

I completely, I've never even looked at that as being something that [my daughter] would need, other children that understand where she is and what she's going through . . . just [being] around other Wounded Warrior kids who have issues and whose dads have been in and out of hospitals and have said terrible things.

Our children don't lead normal lives. My children can't come in and scream and play and have a lot of havoc in my home because my husband can't handle that. The kids didn't have friends come over and stay the night because I just—[my husband] wasn't stable and I didn't want that type of behavior to happen with someone else's child at our house, church people or what not. So that was really difficult.

If [my child] were to go to a civilian [therapist] who had no experience with military and [she] said, "My dad got really upset and threw our china hutch," for a civilian provider, they could call Child Protective Services and report it.

No, no. There are no resources [for the children].

Finances as a subtheme of the turn. Another opportunity to appreciate their reality is revolved around the issue of finances, making ends meet today, and expressing concern for the future. It was a very real and immediate concern for the caregivers, most of whom were very vocal about this. Regardless of rank upon retirement, finances remained a high priority, as the majority of the women were in a position where they had to stop working in order to provide care, thereby relying solely on their husband's income.

I had a good job, making [good money]. When I left my job [in 2012 to care for my husband], we lost all of that . . . and it's been a struggle ever since. We need more

money, but I can't—I can't work at a full-time job, and not be available for the things that he needs, and to make sure that those needs are met.

If my husband was to walk out the door, there is nothing. I have not paid into Social Security. I have no retirement. There's pretty much nothing . . .

I do remember a time when there was an issue and thinking to myself, what am I gonna do? I've only been a caregiver. I had no money. Everything is tied to them, and so I guess that was kind of an empowering moment too, is saying, "No, I don't want to feel like that, so I need to start getting myself together so that I don't feel like I'm here because I have to be, I'm here because I choose to be here and I choose my husband.

Acknowledging the role of caregiver as a subtheme of the turn. The acknowledgment of *the role of caregiver* took from one month to many years. For some, the only model they had was that of caring for the elderly, the physically impaired, or those needing institutionalization.

I actually started serving as a caregiver prior to ever knowing that's what I was doing.

I thought caregivers fed old people and helped the elderly get around. The nurse protested and said, "Oh, no, you can be a caregiver for someone with a brain injury or mental illness." I said, "No, no, no. I'm just his wife. I do all of this, but I'm just his wife." That night when I went home, because my husband was still in the hospital, I searched the caregiver term. That really opened up a whole new window of what I was going through.

I thought you had to be paralyzed or have a spinal cord injury because the way that I interpreted it when I read about it, was that it [caregiving] was for the most severely . . . for people who would otherwise be in an institution.

Having now begun to make better sense of the situation, given the benefit of time, resources, and understanding, the story of Nicole and Mason beautifully illustrates the patience and practice that goes into implementing on-going, effective strategies, along with the realization that one is, indeed, a caregiver. As Nicole says, "It's taken us years." The subtheme of acknowledging the caregiving role and the plot element of strategy(s) are italicized in Nicole's story.

Nicole and Mason. Nicole remembers everything that happened that night in 2006. Her husband, Mason, had been injured while on active duty in 2003. *Returning with severe*

burns to his hands, face, and chest, a cauda equina spinal injury, TBI and PTSD, it wouldn't be until three years later that Nicole fully realized the extent of his injuries and her role as a military caregiver.

“We were at a party and he wasn't himself, like he didn't really know where he was, so we left. On the way home, he was driving, and we were going underneath an overpass and he just freaked out. He just went into straight combat mode, pulled the car over, got out, shattered the windshield, and was just freaking out, screaming ‘Get out, get out, we've got to go! Get away from the car! It's going to blow up! Get out!’ I didn't know him at that point. I'd seen some strange new stuff [before], but nothing like this. Everything was black in his eyes; he wasn't there. I locked myself in the car. I wasn't getting out.” “So I just—I left. I drove up probably five miles from where he was and realized, ‘Oh my God, I just left my husband in the middle of nowhere, freaking out.’ So I went back to get him, and he was not there. I drove around. I couldn't find him.”

Terrified more for him than for herself, Nicole went to her mother's because she didn't know what else to do. “19 hours later he came home. He had walked home from where we had been. He said he didn't know where he was. He thought he was in Iraq [and found his way home using combat training skills]. *That wasn't my husband and I knew then that our lives were different from that point forward.*”

“It's taken us years to adapt and overcome—counseling, hundreds and hundreds of different kinds of meds . . . a lot of changing our lives, where we live, just finding that middle ground, that comfortable space . . . and we're still learning, learning how to be a team. We learned that living close to our families was not optimal. [In fact], it's our

biggest issue. They just want back what they had, [but] their son . . . is still in Iraq. They were given a new son."

Using her own skills, Nicole says, "I choose my mood every minute, every day. I tell myself, 'It's ok, breathe, choose your action' . . . to make the most of the life we were given." Which is critical for Nicole because she also cares for her aging mother, her combat veteran brother, and has custody of his three children, ages 14, 8, and 1. "Saying 'no' actually breaks my heart. It's probably the worst word in my language and I'm still working on that."

Nicole reflects on her life. "We were dealt what we were dealt . . . and the dominoes fall exactly where they should every day. *[We are re-focusing our] life [from] this is what we thought we were going to have [to] this is what we do have, and just making the most of that.*" And in the face of that reality, her faith and life's control come when she says, "I'm in it for the long haul. The fight is worth it. We're worth fighting for."

I'm Not the Only One as a subtheme of the turn. Stories were told about the time the women realized other people also had tragedies in their lives and that others suffered as well. They realized the reciprocity of allowing for self-help and their own healing would ultimately lead to the possibility of moving beyond the self and helping others, which fed back to them in positive ways.

When you're faced with tragedy like this in your life, you feel like you're the only one, and you get to a point where you're so needy [that] it's just constantly about you. And you just think your life is the worst life on earth, and nobody else is going through half of what you're going through, and it just consumes you. Until you can realize that everybody has something, . . . there's no way to help yourself.

. . . each of them had a different story that was so similar on the level of craziness that it made me feel completely like—I can't even describe it—like, normal. Thinking that it

was us and not realizing until that moment with all these other wives [that] it had nothing to do with me. It had nothing to do with him as a person and it had everything to do with this was a common theme throughout all of these marriages that everybody was going through.

It's amazing to know that there's other women out there who feel the same way because you think, my God, am I the only one that feels this way?

Letting Go of Control/Choice as a subtheme of the turn. The caregivers all eventually found themselves slowly being able to acknowledge the necessity of letting go of their control over their husbands and the situations they were in, thereby giving them free choice in the matter. Paradoxically, they found that by letting go, they began to regain their strength and power.

If he's that committed [to taking his own life], there's going to be nothing I can do, no matter how much control I think I have of the situation . . . focus on controlling my well-being and let go of controlling other things that I truly can't control. The only thing I control is my mood. I can set my mood every day. I can set my attitude every day. But I can't control him.

Part of that fear is—well not a part of it, probably a majority of that fear is not having that control. So it's a huge step for me to step away from that, which I feel is very important for me and my family. It's healthy. That's the realization I came to is that, at the end of the day, I don't have that control.

The pivot points on these time ordered events of the story line are dependent on context, as often another turn in the narrative takes place when there is an outside response that calls forth seeing one's life through the eyes of another. Realizing that there was never any control beyond herself, the story of Jane and Fred is an example of how the image of one's life was unmistakably reflected back in the moment of a stranger's glance. The subtheme of letting go of control/choice is italicized throughout Jane's story.

Jane and Fred. Jane recalls, "The first 6 months was like a honeymoon phase of having Fred home; but after that I finally had to admit to myself that something was wrong that wasn't temporary. This was a long-term something was wrong."

That was 2006. Adding to post-traumatic stress disorder, traumatic brain injury, bilateral hearing loss, and spinal injury, there was “a lot of erroneous spending, crazy thinking, wild crazy thinking, wild crazy doings. He was fixing things that he thought were broke, but they [weren’t]. And then I’d have to come along and try to fix them, or call someone to fix them. He was getting lost in our hometown, and we have a very small hometown, a very rural community . . . He was missing appointments like crazy. He wasn’t able to keep a schedule. He was having moments of his day that were totally lost; no recollection. He was forgetting conversations . . . and it was scary and terrifying.”

Today, “It’s an ever-changing daily new normal. We never know from one moment to the next what we’re going to get from him—lots of ups and downs, but truly a roller coaster ride. He’s declining cognitively and physically. Some days I break down and cry. Some days I literally have to make myself stop, which is not easy.” But “when my husband and daughter are asleep . . . when my husband is safe and sound . . . and nothing dramatic, hopefully, is going to happen while he’s sleeping . . . I take my chance and spend anywhere from an hour and a half to two hours at the gym, and that’s my sanity break.”

Summing up her life with Fred, Jane says, “*This is how we live. I’ve learned to live with the unexpected, with his throwing me the curve ball; I just know he’s going to throw something at me . . . [but] you just learn to live with it. Second nature, ok, move on . . . The kicker for me was, we were in public and someone looked at me mortified, because my husband said something that was—we call it awkward social Tourette’s because he has no filter . . . a total unconscious no filter, and I just went with it . . . and it wasn’t until we got back into the car that I was like, oh, oops. Yeah, that person sure as*

heck didn't get what just happened, did they? And I started thinking about when did it just become second nature, and it's wow, every now and then something new comes along that makes me cry. But for the most part . . . for a few years now, it's just been, OK, this is Fred. Yeah, my husband came home 11 years ago, but we still live with the side effects of war on a daily basis, and it's only going to continue for the rest of our lives. It's never going to get better . . . [so] you just become creative. *You find a way . . . you can't let things hold you down, push you down, or hold you back . . . We've lost friends since Fred came home and it hurts . . . it was too much for them, and some, they either don't want to admit it or they don't know how to deal with it, and you just have to let them go . . . some are just flat out mean and don't care . . . but I have a few girlfriends who have taken the time to care."*

Flexibility as a subtheme of the turn. The caregivers also used the metaphor of "curve balls" being thrown at them, "firecrackers jumping around their feet," or being on a "roller coaster" ride, as a way of expressing how they remain *flexible* and receptive to any situation.

We still have times when he gets depressed, and I'm not sure to handle it, and you would think after years of going through this together that we would know . . . it's just a roller coaster, up and down.

You don't know which direction to go in sometimes, and sometimes the direction you go isn't the right direction.

It's like a roller coaster up and down, and you just have to learn how to roll with the punches, and learn that it's not just all about him, or all about you, and just be a team, and learn how to work together.

Ending Blame as a subtheme of the turn. This was one of the most critical subthemes that each caregiver, in her own way, reached to reinvent her marriage and move forward authentically with love, care, and support.

At our 10-year mark, I stopped blaming him. When I [did that] he admitted that he

thought I wouldn't love him because of the things he had done, the choices he had made [in Iraq] and [worried] I was just there just to give care to him rather than love him. So in May of 2013, we renewed our vows, and promised—we promised to each other that no matter what [had] happened in the past, we are going to let the past be in the past, and move on with each other for the future.

The Ending as the seventh plot element. Following resolution strategies on the story line, the final resolution or *ending* satisfies the conflict of the plot but does not attempt to resolve it. Life events stand always ready to repeat themselves. Again, beyond any attempt to resolve a seemingly unsolvable puzzle, the women spoke into their gritty perseverance and strength that comes from within. Here we see the beginning of a spiraling up of a new trajectory, a stronger, more focused evolution beginning to take place.

Table 4.6 briefly summarizes the different ways in which the seventh plot line element, the ending, was expressed in the women's stories.

Table 4.6

The Ending: The Seventh Plot Line Element

Acceptance	"My marriage is not what I dreamed of but I'm in it for the long haul." "This is my husband; it's an ever-changing daily new normal." "We're in a better place now but we can always go back." "We make the most of the life we were given." "I've accepted this could be what it is."
Rebirth	"This has broken us down and built us back up." "I've rebuilt my family."
Gritty determination	"It would be easy to walk away but I choose not to do the easy thing." "I am fighting for every veteran and caregiver struggling because of burn pits." "I fight for him."
Relinquishment of control	"I've learned to let go, to live with the unexpected." "I wouldn't have been so controlling." "I can only do so much; letting go of controlling what I can't." "I can't control his injury and the choices he makes."
Virtues	"Faith and patience" "Faith" "Loyalty" "I'm a very loyal person." "Respect for my husband; I could never repay him for what he has given."

The Shift as a topical theme. This phase of evolution within the seventh plot element of ending is marked by the grace and equanimity of the beginning of mastery—where the caregiver is beginning to understand and master herself in relation to self and others. Respecting that life does not have to be a particular way, life is now sufficient being just the way it is. This fundamental shift all the while continues to remain fluid, as one caregiver poignantly reminds us, “Even though we’re in a better place now than we were before, we can go back. We can always go back.”

The story that follows of Karen and Will expresses two critical features of military caregiving. Once again, coming full circle in consideration of Bruner's (1986) "psychic geography," Karen takes her story outside of the home and into the unpredictable world. The first critical feature of her story is the experience where the balance in her relationship with Will caused her move into hypervigilant ways of being to help protect him from his triggers, thus providing predictability in the world outside. The second, equally robust feature, provides a natural bridge that tapers down from the climactic point to an ending point by settling conflict in the plot beyond a resolution. There is no light without the dark, no joy without the sorrow. Both must be present in order to experience the richness of life. For Karen, as for many others, her memories were held captive by the dark, but now her life opens freely to the light. Both of these features, which ease the story's ending on the plot line, are italicized for the reader's convenience.

Karen and Will. Karen recalled, "In about 2011, my husband, Will . . . knew something wasn't right and he sought out help on his own, without me. When he came home he said he had been diagnosed with PTSD and for me, that clicked. I started to feel really foolish that I hadn't known [but] I just hadn't put the dots together. With those 4 letters, everything made sense to me . . . and I dove into researching everything I possibly could."

Will completed eight weeks of outpatient therapy and he was cleared for duty again. "OK, you're good to go [they said]. You're cured, so just continue on." Then we transferred "and he was with a training group he had wanted to be with for a long time. We were managing his symptoms. He was medicated and going to therapy. But memory issues and these headaches were [surfacing]. One day he was trying to teach something

that he knew forwards and backwards and had so much experience with, and he couldn't remember. He couldn't remember what he was teaching while he was teaching it. He was taken to the hospital and that's when we found out about the TBI." For the next year, Will would go on to complete extensive in- and out-patient therapy programs. But in 2013, "it was decided he needed to be med boarded out of the military."

"I became hypervigilant about everything. I had an impending, something's going to happen, all the time. I would worse-case [every] scenario to try to avoid him from getting triggered . . . it was a mindset of constantly trying to eliminate triggers . . . fantasizing what would go wrong . . . I had a hyperawareness to situations . . . where do I park? Where are the exits? How many people will be there? Suddenly I'm intensely focused on the most minute details . . . It changed how I looked at everything."

Karen's memories always return to the nighttime. "[He had] these incredibly horrific nightmares that [he acted] out on. It's very hard to be with someone who has hurt you, but they're not conscious that they hurt you . . . I never felt abused. It's not that kind of thing. It's a weird space. It's always night and it's always dark . . . vulnerable and alone. And then [he] would have no recollection of it, no memory. But when [the diagnoses] came to light, [I experienced] an intense sense of guilt and shame, embarrassment. I was putting this awful feeling on him [but] he was in no way trying to do [anything] to me."

"My life isn't all black and white and dark and sad. I don't ever want to be a victim of this. It's something we went through . . . the hard stuff is true, but there's also truth on the happy side, too. When I realized this was permanent, I made it a part of my life, but not my whole life . . . and I wrote my thoughts down; it would help me stay positive and focused. The dark and light are interwoven. If [I] just lived in all the

darkness of all the bad days, I don't see how [I] could get out of bed in the morning. *You have to believe that better days are ahead or what the hell's the point?* Am I going to live this permanent situation in the depths of despair, or can I look at the bright side? That's how I want to live my life."

"A lot of people exploit the tough stuff and certainly there's a sacrifice to this life. [But] I don't want people to think that's all it is. We are a wonderful family [and] we're on a path for success. So here, let me show you the light side. Let me show you the hope. Let me show you the love that also [runs through] my story. I don't want to be defined by the dark days . . . it's not my identity . . . I want to be defined as like, wow, she went through that, but look at her now."

Accountability as a subtheme of the shift. It is a combination of responsibility with communication. It starts with the recognition that each one is responsible for her own experience of life. Each caregiver at this point of evolution has realized this and consistently manages herself by assuming *accountability* for the things that are not working in life as well as the things that are.

We just had a lot of relationship issues. Finally, after years and years of fighting, you know, a few months ago we had a huge fight and I told him, I said, "I'm not leaving you." And that's what it came down to, that [I had to] convince him I wasn't going anywhere. It's like, everything else has been stripped from [him], you know. I was never going to leave him and that's all he needed to hear.

I'm not saying that we work around him completely because there are times when I'm like, "You need to go upstairs or you need to go to the basement to hang out because [our daughter's] friends are here." So he's taking some ownership, and we're not making it where we're gonna tiptoe around him anymore, but at the same time recognizing that there is an issue, but also, he owns it where if he's starting to feel stressed out, he knows to go upstairs or go to the garage.

Accountability also exists in the domain of health, and most caregivers reflected on their own health and ways in which they could improve it, even if it were to define what the health condition was.

I'm at [my highest weight] now. I've put on 40 pounds and I know that's due to the lack of activity and then probably eating just for comfort. But my health, I finally managed that I only can do so much.

A lot of caregivers, we don't take very good care of ourselves.

When I about fell . . . first of all, I have diabetes, and I thought all I need is a damn broken bone or a broken hip. My diabetes will go out the roof. And then that is it. Who is going to take care of Mister? My poor girls are raising their children even though my girls, our daughters, do everything for their father just as much as I do, and so do our grandchildren. But that's not the point.

Clarity as a subtheme of the shift. An important side of *clarity* allows for a relaxation to start coming in and realizing that what is true for one may or may not also be true for others. The interpersonal relationships then become about supporting others' processes with compassion. This allowed the caregivers to be able to graciously conduct themselves in their own reality without invalidating the realities of others.

Each of them [in the group] had a different story that was so similar on the level of craziness, that it made me feel completely . . . normal . . . [in] realizing [the circumstances with my husband] had nothing to do with me. It had nothing to do with him as a person, and it had everything to do with this was a common theme throughout all of these marriages that everybody was going through.

Yes, tragedy has struck and yes, it's been several years, but it didn't just happen to me. It happened to many people. And when I realized that, that's when I was able to take the steps forward in fixing what I needed to fix. And I'm still doing that. It's just not an overnight thing.

[I'd be] just looking at them going, "You're being impatient over what? Really?" So, I have realized I've got to stop and breathe, and go, "Wait a minute. Their life is different than ours. It's okay. And their appreciation level is different than our life, and it's okay." And I have to remind myself to breathe.

Advocating as a subtheme of the shift. This was considered by all to be at the heart of caregiving. Most women recounted stories that placed the need *to advocate* as the one thing that supported their husbands who could no longer manage their own care. This was often exposed around medical appointments and the realization that the veteran did not understand what was occurring in these appointments and did not know what to do, what questions to ask, or how to maneuver within the medical system. It was also appreciated that to be an effective advocate takes skills that are not necessarily inherent.

“Well, yes, they said something is wrong with my brain,” [but my husband] couldn’t explain to me what was happening at these appointments. And when I found myself tracking down people in the VA so they could explain to me what my husband was talking about is when I realized I have to be present. I have to be at these appointments. And I have been at every single appointment since.

. . . because I would ask him when he’d come home, “Oh, how did it go? What was the appointment about?” And he wouldn’t even remember and I just thought he was blowing me off, but no. He wasn’t blowing me off. He actually didn’t remember. But I didn’t know that then.

I see time and time again that caregivers struggle with this. They don’t know how exactly to advocate. I didn’t realize that’s what it was. I didn’t realize it was advocating. You need to ask for things. And there is a way of doing it.

So I learned. And I struggled. And I learned. And I listened. And I kind of felt it all out. And I read. And I just informed myself. But I think that advocating is a tremendous, tremendous part of the story.

Advocacy can scale up to include more beyond the one to whom care is being given. In the case of Viola, our next story emphasizes one woman’s response to the critical issue of veterans in general. It is a powerful story of seeing a broader vision. As a way of settling the main conflict, the seventh plot element of *ending* is highlighted in Viola’s story along with her personal shifts in advocacy.

Viola and Eugene. Viola recalled, “We were grilling at home [in the summer of 2011 and Eugene] was on leave. We had the grill close to the house because it was under a back

porch. We had a houseful of people and he always did the grilling, so he was outside doing that. Suddenly I saw a light, it was daylight, but I saw a bright light from outside and ran out to see what it was and the house was on fire. The siding was melting, the grill was too close to the house and it was hamburgers, so the grease had flared up and the siding was melting. He was standing there, staring at [the flames]. He wasn't trying to put it out, he was just staring. I had to yell a couple of times and I grabbed him and pushed him back and closed the grill lid . . . That was the first time that I really knew that something was going on that no one had really pinpointed . . . At the time, he was on leave from Iraq and there's a lot of burning pits and they said a lot of times [the Iraqis] would throw everything in there . . . humans and things. [Eugene] said he just knew what was in [them] and it was just—he remembered all those burn pits when he saw the flames from the grill . . . He didn't even know what happened. He was unaware of his surroundings. It took him a while to come back [to us]. He said he didn't know why he [had done] that, why he had buried that [memory].”

“But he finished his deployment, went back to Iraq and suffered another blast . . . He was home for about 6 months then signed up for Afghanistan . . . where he had his final blast. And that was January 26 of 2012. That was his death day. That's the day he should have died . . . The military out-processed him to come home . . . And then I saw that he was different. He was stuttering, wasn't remembering things, shaking a lot, the classic signs of PTSD and TBI. He just wasn't the same person . . . After a lot of fighting, I had to go Congressional to get him back on active duty so he would be medically discharged and get the care he needed, because he wasn't the same person they [had taken] . . . He came back a sick soldier.”

“Afterwards, he was a train wreck. He was moody, he’d cry, and thought he was no good, wasn’t needed by anybody anymore. He had read his medical file and what the military [had written] about him. That he was incapable, deemed unemployable . . . How does that make a 48-year old man feel in the prime of his life? . . . So he was pretty depressed for a long time . . . [but] I’ve learned to pick my battles . . . You never know what you’re waking up to, who you’re going to have for the day.”

“These invisible wounds are hard . . . We have a ladder secured to the side of our house because we’re trying to find a traveling leak in the roof . . . People in the neighborhood were making snide comments about why is that ladder on your roof? You gonna jump off sometime? You going to shoot up the neighborhood? It’s stuff like that that really makes me mad. Because these people have no idea what he goes through every single day. He had to kill kids in Afghanistan just to come back alive. He lives with that every single day. It’s not funny . . . This is why I’m back in school and studying Justice Administration and Criminology. I want to be a victim’s advocate for the veterans. There’s a lot of them that [mistakenly] go to jail because of PTSD and TBI . . . I see so many of them that are agitated by stupid idiots in the neighborhood or [are provoked by] them and that’s just wrong . . . [I should graduate] by next spring.”

“I have learned how much respect I have for my husband. He’s earned three Purple Hearts. I could not ever repay him for what he has done . . . Yeah, there’s days I don’t like him, but I always love him and I would never leave him.”

The Coda as the eighth plot element. The plot analysis ends with the *coda*, a whole-narrative reflection, discovery, or transformation. In the story of Trisha and David, the *coda* of her narrative ends with the discovery of the strength of reciprocity, the difference she

makes in the world, and the value she brings to it. Through this process, which Trisha sees as “a blessing,” she has connected to a new, stronger identity of herself. The value of her reflection in the *coda*, this final, eighth plot element has been italicized.

Trisha and David. Trisha and David met when they were both young and serving in the military—a time that helped shape her identity as a strong, proud, and loyal young woman, despite having suffered herself from military sexual assault and trauma. But when she hung up her uniform to care for her husband, she lost her identity in service to the roles of David’s wife and caregiver and the children’s mother. “There was no more Trisha, there was no more me. That was it.” She wouldn’t get her voice back until she became an Elizabeth Dole Fellow in 2015.

In 2002, after several lengthy deployments with significant injuries incurred during training exercises and combat exposure, and at a time Trisha was ready to give birth to their first baby, David began exhibiting nightmares, debilitating migraines, anxiety, balance problems, hearing loss, seizures, stuttering, hypervigilance, increased depression, drinking, hopelessness, and withdrawal. By 2004, due to TBI, PTSD, hearing loss, and balance problems, “David was very sick. Those years were my battle and I had to do it alone . . . programs were not there.” At one point during this time, David “had a lot of psychosis. He was hearing voices and he tried to commit suicide.” It was around this time that Trisha realized “everything was falling apart.” She remembered, “We’re talking about a guy that was the leader, the big guy, the one that everybody followed, the one that everybody had something to do with, and I was at a loss.”

So, even though Trisha went back to school to try to understand what was happening to David, their marriage “was on the rocks.” She continued to struggle, but

hung on. With the added stress of David's stroke and a cardiac arrest on top of everything else, Trisha said, "Our issues were just so much . . . you have no idea."

In 2014, Trisha and David were invited to a Wounded Warrior Project couple's retreat and "David kind of did a 180. He got with [a] group and started to become a mentor. He went and got certified . . . and has become a leader again." However, at that same time, Trisha "hit rock bottom" and said to herself, "You know what? I am not ok." And then "it started all over, but with me." But she managed "to survive, say alive, and keep fighting." Now, Trisha and David take care of each other.

"My marriage basically started about 3 or 4 years ago and it became what it is now. David and I have become . . . this blessing because this . . . has broken us down and built us back up so different. We both understand we've got limitations and that there are things that we can do and things that we cannot and we're learning to live with those. I had to get the point where I had to realize that it's ok to ask for help. I'm not Superwoman and so what if people think I'm crazy or broken or whatever? I try to do the best I can so that's all we can do. Sometimes I wish God didn't trust me that much, but I'm here . . . there was enough love to get us through."

As an Elizabeth Dole Fellow, Trisha has found her purpose, just as David had found his. "I knew how important it was to get out of that box because I was drowning in that box and I thought, you know what? No family should go through that by themselves [and] I want to do something about it. These are my people."

Table 4.7 summarizes ending statements from the narratives of the women who so graciously told their stories.

Table 4.7

The Coda: The Eighth and Final Plot Line Element

Found identity	"I found my identity through Fellowship; these are my people." "I'm strong, I am smart, and I know how to fight."
Reflection of choices	"I would have asked for help sooner." "How we want our lives to look is a choice."
Realization of the paradox	"I've learned to be structured but flexible at the same time."
Focus of attention to reality	"Dominoes fall exactly where they should; focus has shifted from what we thought we were going to have to what we do; make the most of it."
Call to action	"It is my responsibility to take action and prepare for the future to impact changes for me and all caregivers." "I am in school to become a veteran advocate." "I found my voice." "I don't ever want anyone else to go through what I went through."

Inspired Action as a topical theme. Embedded within the coda or eighth plot element, is *inspired action*. It is the only thing we have to create results that are workable in the reality in which we live. For the caregivers, this meant results that were of joyful service to themselves and others. In this phase, each military caregiver became a service to herself, her husband, and to others. This act of pure devotion occurred within an appreciation of her own humanity, the dark as well as the light. Never separating the two, they were embraced together as a reminder that one cannot exist without the other.

I am just very passionate about engaging veterans and if you see a veteran, if you see the dog, respect them. They respect you. Respect them. I am just very big on respect. There's so much more a simple cup of coffee or that veteran next door, his wife says he isn't having a good day. Maybe I can go take some dinner or . . . there is so much more that can be, [that] a community can do instead of having a [green] light bulb.

I put myself out there because I don't want another caregiver to feel the way that I felt between 2006 and 2010. I don't want anyone to ever, ever, ever, ever feel that way. So I

have dedicated my life, my time, my energy to those people because I want to offer that support because I don't want anybody to go through it alone.

The darkness of this tragedy brought a lot of light . . . This is the message. This is the message that people need to hear. They need to hear it, even though the struggle isn't over. I know it's not. I know that every day.

The Elizabeth Dole Foundation Fellowship as a subtheme of inspired action. The narratives culminated in appreciation and gratitude for Elizabeth Dole, her staff, and their Fellowship with military caregivers. Beyond any attempt to resolve a seemingly unresolvable puzzle, the Fellows spoke to the strength that came from being connected. Within these narratives, we see the women moving in a direction towards a stronger, more powerful evolution, unique as Dole Fellows. Senator Dole sparked the source of inspiration in each of the Fellows, who now could collectively share a truth that was superior to her individual separation and conflict. These women are now inspiring each other, going well beyond their Fellowship.

I found my voice in a way I had never dreamed possible.

[The Foundation] gives us back confidence, and for some of us it pulled us out of a pretty dark place, just being heard, and being loved, and being able to know that we're not alone. Even though we know that we're not, mentally sometimes it feels that way.

It gave me a voice because I was [my daughter's] mom. I was [my son's] mom. I was [my husband's] wife and that was it. And so those were my roles. There was no more me. There was no more of me.

We don't fight [just] for other caregivers, we are fighting for veterans. We're also fighting for our military. And it's very inspiring.

The story of Elizabeth and Alan is presented as a beautiful example of how one woman evolved into enlightened action through the inspiration of Senator Elizabeth Dole and her Military Caregivers Fellows Program. It is an important story that comes full circle, ending with a moving testament to the work of Elizabeth Dole and her Foundation. The reader's attention is drawn to italicized areas within the story that are consistent with this final reflection.

Elizabeth and Alan. “That moment at the kitchen table in 2009 was my wake-up call,” Elizabeth recalled. “The day that Alan made his first suicide attempt . . . as his wife, how did I not know that he was so depressed that he would try to take his own life? How could I have not known? That’s when I quit school and put my whole life on hold to make sure he was ok.” At that point, Elizabeth told him he had to go into the hospital to get help or she was leaving with their three children. And he did. But there were two more suicide attempts and by 2013, he still hadn’t turned the corner. “I actually had to leave once for him to get help. It was hard. During our separation, there was a restraining order against him; he was not allowed to contact our children. But I still had to do my caregiving role. I still went over to cook dinners, give him his pills, take him to his doctor appointments. [But eventually] I had to call the police [and] he was court ordered to be in a mental hospital for 17 days because it was the only way I could get him to get on any type of medication because he wasn’t himself in any way. [But] I knew that if I stood by him, he could get better. And that’s what he has done. He’s improved tremendously since 2013.”

“It took a long time for my family to get it. [We used to live] with my grandparents. And they knew Alan had PTSD. And they’d go, ‘Is he going to kill me in the middle of the night?’ And I’m like, what did you say? ‘Well, he has PTSD. Is he going to kill us?’ I said, did you really ask me that? I sent you hours upon hours of literature to read. Did you read it? ‘No. I’m only going off what I hear on the TV.’ Well, that’s your first problem. Don’t watch TV. We moved out a week later.”

“I’ve been part of an online community with 20 wives for the past 6 years. Two years ago, I got to meet and hug the woman whose voice made me wake up and get away

from the anger of my situation [and realize] I am the only one that is going to fight for Alan because the VA is not going to fight for him. The doctors aren't going to fight for him. It's me. I mean, I would give any amount of anything in the entire world for my husband to be my husband again, to have him back. I am mourning who he used to be because he is never going to be that person again. And I would give up anything in the entire world to have that man back again . . . Dedication . . . I hold my [marriage] vows very important. When I grew up, I wanted to be married only once, [so] I fight for him. And I'm still here. *I've learned so much. I've learned how strong I am. I've learned that I am smart. I've learned that I can fight.*"

"This wouldn't have happened without the Dole Foundation [and] the people who I've met. I never would have found my voice. We never had a voice before Elizabeth Dole. Never. She is showing the outside world what it is that we do every day. She's our hero because without her, caregivers would be nowhere. We have a voice that fights with us and then inspires us to fight for ourselves. Hers was the voice that got our voices out there."

Summary Analysis and Reflection

Each of the 14 participants shared her story about her experience of being a military caregiver to her post-9/11 combat veteran husband; one shared her story about her husband being wounded stateside. Vignettes were created from the original 14 transcripts, all of which are shared in their entirety. These vignettes were presented as illustrations of the plot elements Daiute (2014) uses to conduct her narrative structure, and were supported by the various themes extracted from the narratives, allowing for the life experiences to be shared between and among

the caregivers' lived experiences. Through the arc of the story lines, a continuous story was captured that was consistent among all caregivers, yet highly nuanced and unique.

The themes that emerged were organized progressively according to the trajectory of the plot line elements. The women spoke of their initial need and hope of finding something external to themselves to help them make sense of their experience, such as their need to believe in the medical system. They spoke of their doubt and confusion with experiences within the medical setting as well as with extended family or friends. They then moved their experiences into a state of being disillusioned by not being able to "fix" the problems, and were realizing that their lives would likely not return to what they had been. Emotions that surfaced were hurt and confusion, shame, anger, grief and loss, depression and anger. They also expressed how stressful their lives had become, frequently using isolation or temporary leaving as strategies. All the caregivers spoke about their children and the lack of resources to help their children move through their own emotional stages. Finances were a very large part of the conversation and their financial security was a very deep concern. These two themes kept the caregivers anchored in a reality that helped them tip into a turning point in their journey. This was marked by acknowledging their role as a caregiver, a realization that they were not alone, a letting go of control, and having choice in the matter, all of which gave way to a more flexible and powerful way of being in their relationships. Now they no longer had the need to blame their husbands for their life's circumstances. Subsequently, a fundamental shift occurred, giving rise to accountability for words and actions, a clarity where they could relax into differences, appreciating and understanding the skills of advocacy, the heart of caregiving, and producing joyful results in service to others, while allowing for both the dark and the light sides of life to arise and co-exist. All of the caregivers were now realistic, knowing life could shift at any

moment, taking them back to the beginning. It was with gratitude and appreciation that each woman expressed her thanks to Senator Elizabeth Dole, her Foundation, her staff, and to their Fellowship together.

Reflections on the Grand Narrative

The Breakfast of Champions

On March 23, 2016, I met my first Elizabeth Dole Fellow at a Breakfast of Champions event, hosted in Los Angeles by the Southern Caregiver Resource Center. There were two young women on the stage with a moderator. As they prepared to speak, I had gotten up and wandered to the back of the room to get another cup of coffee, when I heard something remarkable beginning to unfold in front of the audience. Turning around, I began listening to a young woman on stage as she told the most unbelievable story I think I had ever heard in my life. Without pretense or apology, she told the story of what happened after her husband's final deployment home from Iraq. The horror, fear, and shame that she weaved throughout her story played equal parts to her respect and love for him. Told from a state of elegance and grace, she was calm and assured of her place in the world, as I went in search of a distraction to compose myself. When I finally met her at the end of the event, she was just as friendly and forthcoming as she had been up on stage and I remember thinking, "I wonder how she does it?" In my eyes, she looked so young and accepting. It was not how I expected a military caregiver with five young children, one of whom had autism, would look. I needed to know more about the Elizabeth Dole Fellows.

In Zen Buddhism, there is a phrase called "a turning word." It has been passed down through millennia as a request from the student to the Master. The student would say, "Master, give me a turning word." Here, the student is asking the Master to say or do something in such a way that would awaken the student to experience a sudden realization. For me that day, the day I met my first Elizabeth Dole Fellow, I was taken back to my decades of training as a student and Zen Buddhist priest and experienced once again a turning word, a sudden realization. From that

moment, I knew exactly the direction I was going in my doctoral studies and what I was curious about exploring.

Background

This dissertation has been an attempt to understand the trauma of war and its effects from the perspective of the wives, all Elizabeth Dole Fellows, who stayed behind as the boots on the ground at home. Through their stories of military caregiving, I wanted to bring these women out from behind the shadows.

To paint the broadest stroke of appreciation, I included the most notable features of the challenges faced by the veterans themselves. Beginning with the polytrauma triad of chronic pain, traumatic brain injury, and post-traumatic stress disorder, I felt this was a critical touchstone to begin the caregiving conversation, particularly since chronic pain was among one of the most prevailing medical conditions reported (Girona et al., 2006).

Twelve of the women reported straining against the debilitating effects of their husbands' traumatic brain injuries, some of which went undiagnosed for years. Tanielian et al. (2008) suggest that up to 57% of combat veterans never are properly diagnosed for TBI. Yet, the symptoms run rampant. Thirteen of the women's husbands had a post-traumatic stress disorder component to their injuries. This showed up prominently with devastating stories in the complicating action elements along the plot line. Keeping PTSD out of a psychological realm, it was important for me to look at trauma from a neurobiological point of view. I never wanted to psychologize the women. I never wanted them to feel they had been put into therapeutic categories as their stories were analyzed for this study, and I did not want that for their husbands, either.

Paradoxically, suicidal ideation or attempts were most often articulated as the catalyst that caused the women to finally appreciate how little control they had over their husbands. As catastrophic as the thought was of losing their husbands in this way, it was exactly the ordeal the women needed to square their shoulders to this unthinkable possibility, ultimately realizing that their ability to control anything went no further than the tips of their own fingers.

Their husbands' reintegration home for the final time was left in the hands of all 14 wives, and an expression of feeling they were "flying by the seat of [their] pants" was not uncommon. All became self-educated by reading, showing up at doctor's appointments, asking questions, finding their own resources, and learning from their successes as well as their failures. The six women whose husbands' onsets were more than 10 years ago from the date of this writing were the pioneers in unearthing resources, as very few existed at that time. Depending on geographic location, some women had nothing but themselves in those earlier days.

The Warrior Myth

Throughout history, warriors have left their families and homes for battles in far-off lands, often returning home to insurmountable odds, or what Hazle et al. (2012) refer to in modern day terms as the Reintegration War, proving that "some myths have very real modern applications" (Everson & Figley, 2011, p. 279). Yet the romance we have with the idea of the mythical warrior remains strong.

Accounts of the warrior myth are given in four fundamental story components, beginning with the anticipation the warrior experiences as he takes up the task of war. Junger (2016) writes, "war . . . inspires ancient human virtues of courage, loyalty, and selflessness that can be utterly intoxicating to the people who experience them" (p. 77). The myth continues with the uncertainties and hazards of the acts of war, followed by the homecoming, and finally the

complications or hardships that await the warrior once home (Buxton, 2004). I use Junger (2016) to round out the final component of the warrior's myth:

The sentiment of the tribe [providing a sense of purpose, acceptance, and accomplishment] is such a rare and precious thing in modern society, and . . . the lack of [loyalty, belonging, and the eternal human quest for meaning] has affected us all. It's . . . why—for many people—war feels better than peace, hardship can turn out to be a great blessing, and disasters are sometimes remembered more fondly than weddings or tropical vacations. Humans don't mind hardship . . . what they mind is not feeling necessary. Modern society has perfected the art of making people not feel necessary. (p. xvii)

In their unique ways, all the women I spoke with were clear their husbands were prepared to die for their country. But, upon return home, as Junger (2016) says, “they [were not] sure how to live for it” (p. 124). And that equally affected their wives. Many spoke of how their wounded, ill, or injured husbands were now “just sitting around,” and all were told their husbands were “no longer fit for work or service.” As two women recounted:

He read his medical files, he read what they wrote about him. That he's incapable. We went to the hearing for the disability, for Social Security, and he was deemed unemployable. How does that make a 48-year-old man, who was in the prime of his life, feel? To say you're unemployable? So he was pretty depressed for a long time.

Oh, I think my husband and [I] felt like as soon as you're not good to post, you're not in tip-top deployable shape . . . you become a number, and you're not the effective number for them, so it's like where can we push this guy?

Once combat veterans are out of the military, Everson and Figley (2011) state, “They are no longer ten feet tall and bulletproof because the rules governing camaraderie simply [do] not apply anymore” (p. 281). Physical and emotional injuries as the result of combat exposure make reintegration even more difficult. Exacerbating this ability to reintegrate are problems such as distance to a treatment care facility, inadequate or inappropriate medical treatment, inconsistent or incorrect post-trauma screening, a decrease in federal funding for ongoing economic support for veterans and their caregivers (Everson & Figley, 2011), and the lack of acknowledgment and integration of the caregiver's deep knowledge about her combat veteran and his treatment. All

are problems the caregivers experienced at one time or another and many continue the process of maneuvering their way through these problems to this day.

In considering the mosaic of the lives of these women, sometimes I was too close to see the patterns forming, and I needed to keep stepping back. What I originally termed the “road map” that I first saw emerging in the stories they told me as they traversed through their lives, implied there was a destination to get to, a point in the distance to reach. But what I eventually came to appreciate is that the lives of these women were not so much about finally arriving somewhere as much as they were about adapting, moment by moment, and dynamically adjusting to the dance they were in with their husbands. Over the course of their three to 13 years, even though they had been led through many near-impossible moves by their partners, they were still dancing.

This long view over the years, retrospectively, was auspicious. Over the many years the women traveled across their stories, I learned almost as much about their husbands as I did about the wives. I came to understand what van der Kolk (2015) meant when he talked about imagination and how it is that victims of trauma can only see life through the lens of their trauma, looking at the world in a fundamentally different way:

Imagination gives us the opportunity to envision new possibilities . . . It fires our creativity, relieves our boredom, alleviates our pain, enhances our pleasure, and enriches our most intimate relationships. When people [who have been traumatized] are compulsively and constantly pulled back into the past, to the last time they felt intense involvement and deep emotions [as one would in war], they suffer from a failure of imagination, a loss of mental flexibility. Without imagination, there is no hope, no chance to envision a better future, no place to go, no goal to reach. (p. 17)

We are all profoundly connected, social creatures. Our brains are organized in a way that causes us to want to be with one another and interact together. When one member of the most important dyad in the family became immobilized with an inability to engage fully, as was

evidenced by the trauma expressed in the Fellows' husbands, the evolution of their husbands' lives became halted. Their wives now intensely engaged in the parts, the unbearable states, of their husbands—their anger, numbing with substances, hypervigilance, withdrawal—that represented the landscape where their husbands' trauma was stuck (van der Kolk, 2015). To manage their husbands and their households, the wives were challenged with presenting a calm, safe, ever-present presence for their husbands, despite their own internal states of turmoil, anger, disbelief, and helplessness. In this process, they placed themselves second in line.

The Long Road Home

In this section, I will attempt to integrate the women's narratives to show them as full human beings, honor their shared collective experiences, help us all understand a little better how we see ourselves in the world and, perhaps, allow a glimpse into that ubiquitous question that started it all in my mind, "I wonder how she does it?"

The topical themes, supported and enhanced by their subthemes and embedded in the progression of the plot elements (plotlines are identified within each theme and further identified in Figure 5.1), are appropriate to use as a way to begin understanding the leap the women took into their evolutionary process of being married in an entirely new way. It began with hope.

Hope. As defined by Emery (1978), entrepreneur, executive coach, and one of the fathers of the Human Potential Movement, "Hope is the expectation that some source external to ourselves is going to save [us] . . . Hope is what keeps all the suffering in place . . . hopelessness is finding out that it is up to you" (p. 37). This is a delicate definition against the backdrop of trauma, but ultimately, it is what had to be realized and acknowledged by each woman. Hope drove the women to action (Plotline: *Initiating Action*). She had to learn that whatever happened, it was ultimately up to her and she had to be strong enough not to yield. She had to

think logically and meticulously for herself on behalf of her husband to find the best path for them.

Emery (1978) posits that we all seek “forms” (p. 37) which are beliefs, activities, acquisitions, hoping one or a combination of these forms will relieve the perceived problem. For the Fellows, this showed up as *if only* behaviors or the *belief* that the medical system would solve all their problems, when in fact, it sometimes added to their burdens. But relief was felt when hope gave way to the belief there was some control over the circumstances. And in the beginning, this was necessary. The women were just trying to survive, and they did it in the only ways they knew how. The emergent condition that allowed movement into the next topical theme was the reintegration of the combat veteran and the family into civilian life. The entire purpose now was to understand her husband well enough so she could help them all transition into a new life. No longer a romantic myth, this was an enormous battle for the women, one of whom gently pointed out to me, “You have no idea.” This simple comment brought me back to myself as I was reminded that, indeed, I had no idea, no fantasy of this life. The most I could offer was my sincere and grateful attention.

Unraveling. Pretenses were beginning to be penetrated and the beginning of this newly formed life was being recognized. Suicide attempts, flashbacks, and disruptive behaviors were common at this stage with the combat veterans, and many of the women were beginning their descent into the abyss. These events complicated the women’s earlier approach to problem solving their predicament (Plotline: *Complicating Action*). Most did not know what they were doing or where they were going. There was no past history upon which to hang their experiences and they were quite literally making it up as they went along. They had to trust their instincts, trying desperately not to become derailed by their emotions.

Disillusionment. The emotional expressions I began to hear at this point were fully revealed, expressed, and eventually acknowledged. Shame, grief, loss, depression, and anger were very common. These were places to rest for varying periods of time. These difficult emotions may still cycle back today.

The women knew exactly what they wanted. They wanted their husbands back, the men they had married, and the lives they had had before the injuries or illnesses. They wanted what they had loved best—the men who had been left behind in Iraq or Afghanistan. Yet they knew it was no more than a longing. Life continued on, regardless of their desires. In their own time, they each came to accept the hand they had been dealt, all had moved forward into a future newly created, and answers were now beginning to be understood as being in their own hands (Plotline: *High Point*). The two emergent subthemes that allowed movement into the next topical theme were children and finances.

The Turn. Children and finances were powerful reminders for each woman that life was now different and that she was the only one who could be responsible for managing both areas. Although this added burden was stressful, it also gave her something significant and concrete upon which to focus. As a Dole Fellow, several women chose either children or finances as their platform for change (Plotline: *Resolution Strategies*). Normalizing the home environment as much as possible for the sake of the children also helped the combat veteran ultimately take responsibility for his own behavior. It was also in this stage of the women's evolution that pretenses were beginning to fall away. The narratives became more flexible and the women spoke of adjusting to whatever arose. They were becoming facile with the moods and behaviors of their husbands, despite sometimes not knowing what to do, but realizing no matter what was occurring, it was only temporary. They were easing into their newly defined

spousal relationships with less resistance and more awareness, and the veterans were learning how to take more responsibility for their behavior in the home. Yet the women wore their progress loosely wrapped around their shoulders, always remembering that life was never guaranteed and they “could always go back.” The emergent subtheme that allowed movement into the next topical theme was to stop assigning blame.

The Shift. In order for the women to move beyond all that they believed was wrong in their lives and marriages, they realized they had to stop blaming their husbands. Only at that point could they fully surrender as an existential act that they caused (Plotline: *The Ending*). They took a stand for their husbands and their marriages and moved forward together for the future. Opening up within this created future was the woman’s capacity to stand and account for her own responsibilities to herself and her husband, one of which was to acknowledge her role as his caregiver. The ability to see herself within this newly defined role gave way to seeing herself more clearly and honestly. She began to respect that the devastation of trauma was not exclusive to the military, that everyone experiences their own ways of suffering, and that how others responded to her were neither bad nor wrong. Everyone has his or her own way of being with life’s hard disruptions. The emergent subtheme that allowed movement into the final topical theme was advocating.

Inspired Action. Advocating became a critical aspect of the caregiving role, as all women believed it to be the heart of caregiving. Learning to advocate effectively and passing the skills on to others was a powerful way in which the women began to give back their knowledge and experience (Plotline: *Coda*). This was an area in which the Elizabeth Dole Foundation played a critical training role, showing the women what could be possible with skillful advocating.

The women had now run long courses with their husbands and, as much as it was possible, they had a clearer idea of where they were headed. Predictability was emerging from the chaos. They had gone through the void and had come out the other side. They knew the only way they could keep moving forward was to commit and keep re-committing to themselves, their husbands, and to a higher purpose. They gave themselves credit for their intelligence, strength, and determination, all the while being eternally devoted to their marriages and the future of their lives with their wounded warrior.

They all spoke of Senator Elizabeth Dole, as well as the Foundation’s staff and the Fellowship, as being the source of their inspiration, who fought with them and “got [their] voices out there.” For those who are in an alumni status, the Fellowship continues to remain a significant connection across the United States and Puerto Rico and is an expression of best practices for all military caregivers.

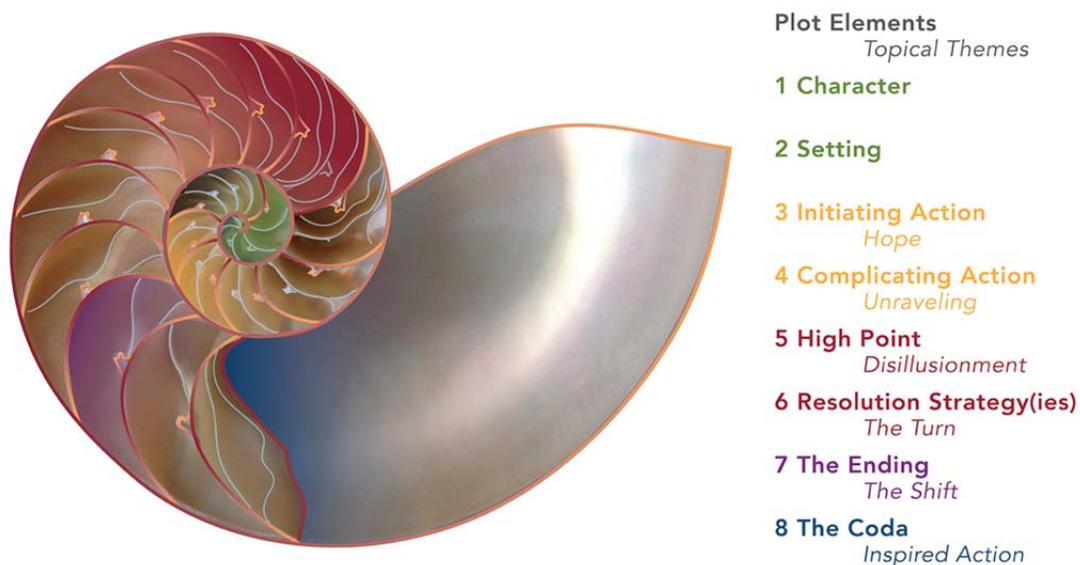


Figure 5.1. Schematic of the plot elements with topical themes. Copyright 2017 Jennifer J. Hunter.

The Nautilus Shell

When viewed in cross section, the ancient symbol of the nautilus shell is a beautiful metaphor to represent the movement of the women through their growth and how their lives were pulled up from their own trauma (see Figure 5.1). The hard outer shell protects the soft body of the animal. The chambers are designed to keep the shell buoyant and moving. As it matures, the animal's body moves into a new, larger chamber, thereby completing another cycle of evolution, revealing how things grow and unfold in steps. Each chamber holds its own knowledge and wisdom, crystallizing the inseparable relationship of the part to the whole. The mysteries of the unfolding of life are granted to each of us, as we are reminded by this wondrous shell that has been replicating itself for 500 million years (Sacred Geometry, n.d.).

Reflections

The *Book of Equanimity*, first published in 1224, is a collection of 100 advanced Zen koans (master to student dialogue case studies) that Zen masters use to this day to train and illuminate their students. Case 20 from the *Book of Equanimity*, "Jizo's Not Knowing is Most Intimate" (Wick, 2005, p. 63) reads:

Master Jizo asked Hogen, "Where are you going, senior monk?"
 Hogen said, "I am on pilgrimage, following the wind."
 Jizo said, "What are you on pilgrimage for?"
 Hogen said, "I don't know."
 Jizo said, "Not knowing is most intimate."
 Hogen suddenly attained great enlightenment.

The beginning of Zen in China started with Bodhidharma's response, "I don't know," when Emperor Wu angrily asked him, "Who do you think you are?" The beginning of each of the 14 women's journeys began with "I don't know," when confronted with their unimaginable traumas. Thoughts, beliefs, and resistances had to drop away, so that in due time, something

new and authentic was allowed to be revealed. When I asked one woman how she lived the way she did today, she simply replied, “I don’t know.” It was a profoundly honest answer.

I struggled to stay in this “not knowing” throughout each interview, each reading and listening of the transcripts, to not presume I knew or understood anything, because I didn’t. In Zen training, this not knowing, this willingness not to be the expert, we would call beginner’s mind—the capacity to explore, observe, to stand in wonder and see things just as they are. Very easy words to write. Yet, imagining myself in any of the women’s places was nearly impossible. My background and training in traumatic brain injury and my own experiences with and beliefs about caregiving were huge demons to confront, and often left me feeling sad for the interrupted lives of the women, frustrated that they were still operating on the edges, and tired and depleted from the weight of their stories. I wanted to connect with each of them physically and hug them all.

After the first few interviews, I started feeling very protective—a silly notion that the women somehow needed my protection. I realized thinking that way diminished and disempowered them, giving no justice to their hard-won lives. I was the one who needed protection from myself as I entered into their narratives with them. I righted myself quickly as I realized how capable and strong they were. The glory of this perseverance they had in their marriages was echoed in, “I choose not to do the easy thing.” None of them chose to do the easy thing. That was the fortitude that allowed each of them to move through her own disillusioned conditions of shame and embarrassment, grief and loss, anger and depression, in order to reach the other side where an inspired calling could be heard. They did not do an end-run around any of this. They did not choose the easy way out.

I heard the pride of place these men had taken in the hearts of their wives, and I was silenced by the presence of the grace that was revealed in their stories.

If Master Jizo were to ask me today, “I wonder how she does it?” I could earnestly say, “I don’t know.”

The Chinese Tangram

The Chinese tangram is a flat puzzle made up of seven shaped pieces, or tans. These tans can be arranged into many different shapes or geometric designs, the objective of which is to form a specific shape using all seven pieces. The tangram is also referred to as a transformation puzzle—transformation, because moving just seven pieces around can create infinite, miraculous changes on the board. I viewed this dissertation process as if creating newly formed tangram shapes with each woman’s story. Moment by moment, every tan of the puzzle, every connection, linkage, every conversation represented unknown possibilities and new understandings.

Nine deep bows to the 14 Elizabeth Dole Fellows who created for me the vast, rich spaciousness of not knowing. Your incredible stories captivated me, taught me, and ultimately expanded my belief in the power of the human spirit with its gift and capacity for transformation.

Discussion and Implications

This story is as camouflaged

As his uniform

We hide behind the guise of right

When there is no right

I want an audience with those who signed off

I want to ask if they care

Promises broken (Comeau, 2014, p. 37) Reprinted with permission

Introduction

Standing back from a story that captivated me, I began the journey of this narrative inquiry from a state of wonder. When 14 Elizabeth Dole Military Caregiving Fellows opened their worlds and presented themselves to me, their stories, memories, and humor shattered my reality, allowing space to arise for an expanded view of human nature when confronted by a catastrophic injury.

In the fourth chapter, Narratives and Analyses, the topical themes that evolved from the narratives of the women included hope, an unraveling, disillusionment, a turn, the shift, and an inspired calling. These were the mutual parts of all the narratives, individually expressed, that gave shape to the women's experiences over a particular span of time. Chapter four looked at their lives in pieces. Against the relief of their fractured backgrounds, it was important that I allowed enough uninterrupted space in chapter five, Reflections on the Grand Narrative, to put their stories back together, to reconstitute the pieces of their narratives, and present the stories of the women's lives as wholly integrated once again. In this final chapter, I turn to discussions leading to the implications for practice, the study's limitations, and suggestions for future research.

The Silent Ranks

From the widest perspective, the contrast between military and civilian cultures is profound. According to Rothman (2011):

The link between civilian and military culture is gone. Instead, the military has a culture of its own. Civil society is organized around the virtues of friendliness and tolerance; it's gender-neutral, with male aggressiveness kept to a minimum. It's cushy, comfortable, and consumerist. It fiercely defends the rights of individuals to express themselves. The military world is opposite. It's authoritarian and group-oriented, tough, disciplined, aggressive, male-dominated, and physically arduous. (p. 1)

It was the military culture that bred these women, imbuing them with a strength that equaled, or possibly even surpassed, that of their veteran husbands. These women's perspectives were different from their civilian counterparts. They saw themselves and the roles they assumed in their relationships as, above all, being in service to their husbands. According to Gross (2009):

Military life is a culture unto its own. We have different priorities, values, time management schedules, rules, and even language . . . Military spouses follow their men wherever service takes them. We serve beside them quietly—providing stability at home. That's why we are known as “the Silent Ranks ” . . . We are second in our marriages. This fact can be difficult to comprehend and accept, but it's the bond we share. Those of us in the Silent Ranks wear that badge of honor proudly . . . It is not [a fact] easily understood by civilians. (pp. 81–82)

These women now became exemplars in providing what was needed in the home, embodying a collective wisdom of their own in service to their husbands.

Over 2,300 years ago in what is now Northern China, military leaders recorded their own collective wisdom into a treatise, which eventually would come to be known as *The Art of War* in the West, or in China as the *Sun Tzu* (Tzu, 2001). This brilliant training of warfare conduct continues to train how to work directly with the conflicts in one's environment, on the battlefield, and within oneself by not ignoring it, giving up on it, or trying to deny its existence. It is a training in how to act quickly and dynamically in response to highly challenging and

demanding situations. Each woman in her unique manner entered into this tradition that the *Sun Tzu* called *warriorship* (Boyce, n.d., para 14).

Many of the women I spoke with, I would imagine, would dismiss the idea of warriorship as applying to them. They thought of themselves as the military wives they were, whose commitment and loyalty kept them in service to their husbands as they now began the slow, painful battle of reorganizing around new, unpredictable lives.

Reintegrating With Post-Traumatic Stress

According to McFarlane (2010), “one of the greatest challenges to the field of traumatic stress has been the observation that many individuals who coped at the time of their traumatic exposure became unwell at a later date” (p. 3). This was supported consistently in the narratives of the women, many of whom went through a honeymoon period devoid of symptoms for many months. Because of the unpredictable nature of PTSD, it was also in large part why reintegration and stabilization for the family was ultimately so difficult. According to Bryant, Creamer, and O’Donnell (2008), research is now showing that the majority of people who develop PTSD initially do not meet the diagnostic criteria for the acute stress disorder. We are reminded of one wife who said in reference to a very significant, delayed first flashback incident, “I’d never seen [anything] like this; he just wasn’t there.” Many questions lie unanswered as to why this delayed state of PTSD only manifests at some future point. McFarlane (2010) suggests that, “Increasingly, the evidence would suggest that sub-clinical symptoms [of PTSD] leave the individual at risk for progressive activation with further environmental stress or trauma exposure” (p. 4). In other words, there seems to be a progressive accumulation of risk that includes the fact that we live in a dynamic environment where stresses from life and past traumas continue to interact (McFarlane, 2010, p. 5). And it was at that exact intersection of interior

wounds with exterior life that the women found themselves intervening. Booth et al. (2007) indicated in their survey that “43% of U.S. Army spouses reported that adjusting to changes in their spouse’s ‘mood/personality’ upon return from deployment was one of their greatest challenges” (as cited in Vasterling et al., 2015, PTSD and Family Functioning para. 1).

According to B. K. Jordan et al. (1992), this is especially concerning, as personality and mood changes have been shown to be critical determinants in family adjustment issues. For the women in this study, little was as stressful or anxiety provoking as learning how to move in the direction of the rage that was triggered within her husband. These were humiliating, devastating episodes that each woman had to confront within herself.

From the pragmatic viewpoint of everyday life and living, the fundamental brain changes seen that give rise to the co-morbidities in PTSD, frequently compounded with traumatic brain injury, are where the women had no choice but to focus their attention. Trying to reconcile opposing tensions took masterful effort. On one side was the need to manage life predictably to reflect a steady, calm, and safe environment. On the other side was the simultaneous need to change instantly to meet head on whatever was occurring. A “roller coaster” was the visual the women spoke of most often as they maneuvered their lives, meeting at the intersection of these two opposing tensions.

Military Service—A Life-Long Obligation

Adding to the weight of this, the family structure can become dominated by the military, even after the service member’s formal separation. For those families who experience uneventful terms of service, they are able to make clean breaks with the military, would likely hold the military positively in the stories they told, and their reintegration into civilian life would likely be relatively seamless. However, for those who suffered greatly over the course of their

service, as did all of the Dole Fellows' spouses, they will remain connected to the military through disability pensions, healthcare, and caregiver's stipends. According to Burland and Lundquist (2013), "[These families are] less likely to reintegrate fully into civilian society" (p. 175) because unlike the others, they cannot make a complete break from the military.

Continuing to articulate what each woman in this study already knew, Burland and Lundquist (2013) state:

There are profound, often lifelong, consequences for the families of combat veterans who were disabled as a result of their military service. This falls most heavily on the military spouse. Just as the soldier's spouse is unofficially relied upon by the DoD to support the military's aims, spouses of disabled veterans take on a major role where VA health services leave off . . . The multiplying economic and emotional effects of intensive caregiving responsibilities carried out across the life course and possibly even into old age is a critical way in which military service quite literally becomes a lifelong obligation. (pp. 23–24)

In this exchange of benefits for sacrifice, military caregivers are in a long-term relationship with the military. But do the benefits match the sacrifices made? Certainly the women in this study did not feel the economic benefits matched their husbands' sacrifice. Once again, the strong reminder of one of the women whose caregiving stipend had recently been significantly reduced, "I'm 24/7. It's like you're an on-call nurse every single day of your life with no days off. And I realize that if they actually compensated caregivers the way that [we] should be compensated, we would run this country broke." Finances were one of the most ubiquitous issues articulated by the women as they spoke about the lack of a financial safety net for their futures.

Military Family Caregiver Identity

Most of the women in the study self-identified as caregivers only at the point of a crisis with their husbands, and for some it was many years after repeated crises, particularly suicide attempts. A parallel feature to this is the fact that, despite the resources, many military

caregivers underutilize support services and are not reaching out for help. The Elizabeth Dole Fellows are uniquely different as caregivers. While they may be the voices representing millions of military caregivers throughout the United States, they are not typical. The Fellows have come out from behind the shadows and are actively engaged, where many others continue to remain silent and unseen, existing as if in an “underground network” (Van Tilburg, personal interview, April 18, 2017).

Perhaps one way to begin to speculate as to why there are so many military caregivers who do not self-identify, thereby understanding why many resources available to caregivers remain underutilized, is to look at the developmental process of caregiving through the lens of identity. I begin with two basic definitions.

Identity is defined by Stets and Burke (2005) as:

a set of meanings that define who one is in terms of a group or classification (such as being an American or female), in terms of a role (for example, a stockbroker or a truck driver), or in terms of personal attributes (as in being friendly or honest). For the role identity spouse, for example, the identity would include what it means to the individual to be a husband or wife. These meanings, which define who one is, serve as a standard or reference for assessing self-relevant meanings in the interactive situation. They represent what the self-relevant meanings in the situation should be [and] . . . they are dynamic and changing. (p. 43)

One of the outcomes of the RAND study (Ramchand et al., 2014) was to provide a consistent definition of the term military caregiver. This was a critical first step.

We [RAND] use the term *caregiver* to refer to the individual, who may be a family member, friend, or neighbor, who provides a broad range of care and assistance for, or manages the care of, an individual with a disabling wound, injury, or illness (physical or mental). We use this term generically throughout the report to include anyone who serves in this capacity, regardless of whether they are related to the individual, live with the individual or are caring for a person with injuries or physical or mental illness. They may provide this service part or full time . . . *Post-9/11 military caregiver* refers to a military caregiver providing care to a service member or veteran who served in the armed forces after 9-11, 2001, regardless of whether he or she also served prior to 2001. (p. 4)

Following a literature search to examine the development of caregiver identity, Eifert, Adams, Dudley, and Perko (2015) identified five major, interconnecting themes noted among caregivers of patients with chronic diseases that addressed caregiving identity development.

These five themes were:

1. Role engulfment and losing self
2. Loss of shared identify
3. Family obligation and gender norming
4. Extension of former role
5. Development of master identity

Eifert et al. did not address military caregivers and there appears to be no existing literature specific to this subset of caregivers on this topic. Therefore, inferences to the military population are made from the review of Eifert et al. on caregiving identity.

Role engulfment and losing self. In this phase, the wives' identities are reshaping, but they are generally too consumed to consider themselves as anything other than, as one Fellow said, "just a busy, stressed out housewife," and again, this initial stage of development can last for years. However, over time, they may begin to recognize their identity as wife has "gradually [come] under pressure . . . their inexperience, increasing isolation, additional responsibilities and loss of [their spouses'] abilities make adjusting challenging . . . as many begin to focus on what they had given up to be [a caregiver]" (Eifert et al., 2015, pp. 360–361). Being consumed now by the responsibilities they have taken on, there is decreased time for behaviors or activities that had previously defined them. The narratives of the women in this study corroborated Eifert et al. in that many of the Fellows talked about their isolation, lack of outside activities, decreased relationships with friends, and all-consuming responsibilities for daily functioning. Yet, the

wives also believed they were the only ones who they could trust to take care of their husbands, or who their husbands would allow to care for them, adding to the double bind the women continuously experienced. However, they also expressed that, had the circumstances been reversed, they believed their husbands would have reciprocated and cared for them. One Fellow commented, “I very much have the husband that would be doing this for me if the roles were reversed.”

Loss of shared identity. The idea of the spousal dyadic relationship requires two people and cannot continue without the other. In reviewing the caregiving stories of the women, the idea of couple was either diminished or was lost over time. Decreasing cognitive functioning in the spouse can affect intimacy, reciprocity of shared responsibilities, and physical and emotional closeness. Identities were in transition as many of the women newly defined themselves in relation to their spouses, now shifting from wife and lover to provider, manager, and protector. For example, one area some spoke of with regret was their spouse could no longer carry on “a 30-something conversation” with them any longer.

Family obligation and gender norming. Societal assumptions and beliefs suggest that providing care to a spouse is presumed. It is an expectation and moral obligation. However, a study conducted by N. Hughes, Locock, and Ziebland (2013), found that “[if participants] willingly chose to be the caregiver and the recipient was grateful, [they] often embraced the role and identity of caregiver. However, if the role of caregiver was forced upon them, participants often resisted the role and the identity” (p. 362). Even though the N. Hughes et al. study did not include military caregivers, the Fellows primarily felt the role of caregiver was not a welcomed role, and they had never had any intentions of becoming a caregiver as a career, which may have been one reason why some women took time to self-identify.

Extension of former role. Extending from the above, role identities shift and begin to normalize within the context of lives that are ever-changing as the identification of caregiver begins to develop. However, Henderson (2001) states, “*Caregiver* may be an identity some aspire to be, but for others an identification of caregiver bears no similarity to their own construction of their role within a partnership” (p. 155). Unwittingly, the label *caregiver* can be prematurely used by professionals before the individual is ready or accepting of it. This phenomenon was very significant in several of the women’s stories and is critical to underscore.

As a term, caregiver was considered by all but two women to be a role with which they initially could not relate. For the majority, it took extended periods of time. The idea of a caregiver gave the impression of someone caring for an elderly patient in a nursing home or a psychiatric institution. It was an antiquated term in the minds of the women, reserved “for old or sick people,” despite the fact they had been functioning in the capacity of giving care to their young husbands, as defined by the RAND study (2001), from the beginning. Of note, the two women who most readily self-identified as caregiver were in their fifties and sixties and had been married to their husbands for over 30 years.

Development of master identity. This phase of development takes over when caregiving takes on the dominant role, replacing any other significant identity. In addition, others begin to identify and refer to the spouse as such. This role, now being so dominant, leaves no time for the caregiver to engage in activities that once defined her sense of self. Results of a study conducted by Dickson, O’Brien, Ward, Allan, and O’Carroll (2010) on the spousal caregivers of spinal cord injured individuals indicated:

Many of the participants stated that their only value was as a caregiver and that assuming the role of partner caregiver resulted in them becoming invisible to other people— that their well-being became secondary to that of their injured partner. (p. 1112)

This finding is also believed to apply to our military caregivers. The “invisibility” of their identities may in part be self-imposed, as many remained isolated and did not take refuge in the help that exists, especially in brick and mortar resources. Some anonymity can at least be maintained on the web, which is how many caregivers across the nation establish connections. Some of the women in this study spoke of their shame and embarrassment, and some were terrified at first of their husbands’ behaviors. Some spoke of feeling they did not fit into their civilian communities and had to protect their children and themselves from neighbors they came to realize did not understand them. In lieu of this, it is presumed that if the identity of caregiver is rejected by those who are actually providing the care, N. Hughes et al. (2013) conclude that caregivers “may continue to be hidden and potential sources of help and support may remain underutilized” (p. 79).

This was the conclusion also reached by Van Tilburg (personal interview, April 18, 2017), as verified by her experience of more than 30 years of clinical, administrative, and policy work in both the geriatric and military fields of caregiving. Speaking of the post-9/11 military caregivers, she further commented that they often take a step back in their own care, allowing insufficient to no time to take care of themselves. Meanwhile, vital resources designed to care for the caregiver go unused, even ultimately running the risk of becoming defunded. Additionally, it was extrapolated from the narratives that the reason the women took a step back in their own care was because they were still placing their husbands first. His needs superseded all else, and the women would give up their own health to take care of his.

Summary of Caregiving Identity

The caregiving stages of role identity shifts that were articulated in the narratives of the military caregivers in this study paralleled the experiences of role changes in caregivers of

patients with chronic illnesses, as researched by Eifert et al. (2015). Therefore, this finding may serve as a beginning to particularize general caregiving identity development to that of the military caregiving population.

The Military Caregiver as Key Change Agent

The demands of caregiving continue to increase as veterans' health issues become more complicated. Deteriorating physical and cognitive functioning causes bodies to break down. As veterans age, so do their spousal caregivers. Many caring for post-9/11 veterans "could look forward to another 50 years of caregiving" (Van Tilburg, personal interview, April 18, 2017).

According to Rudolph and Stamm (1999):

Most [administrators and policy makers] are not trained practitioners of the fields they administrate and thus do not have direct knowledge of the challenges in providing services, teaching, or doing research . . . Policy makers have to rely on information they are given, which is more likely to come from business and financial researchers than from those doing the work under consideration. (p. 279)

The Dole Foundation has already begun to have an impact in this gap through their Hidden Heroes' goals. It is the Fellows themselves raising awareness in businesses, communities, and with civic and government leaders in how to take action in support of caregiver needs. This highlights that not only Dole Fellows but all military caregivers must become their own key change agents. They will need to continue to unite and stand up for themselves and each other to build a foundation of awareness to obtain and sustain the necessities needed to support their needs today and what they project their needs will be in the future. Military caregivers need to stand squarely in the middle of the equation. When caregivers' needs are satisfied emotionally, physically, and financially, the veterans and their children are naturally served.

It will take bold and audacious action for caregivers to unite and stand up for themselves. And they can. The Elizabeth Dole Foundation provides a critical service with its framework of training, promotion, and support of their Fellows in advocating for their needs. But to keep this in perspective, these Fellows represent a drop of green in a sea of blue. There are millions of military caregivers who have not stood up whose voices are needed.

Rudolph and Stamm (1999) admit, “Policy is a slow, cyclical process . . . compromise, perseverance, and respect for small changes are requisite skills. We [should] pick our battles well” (p. 281). Fortunately at this time, the languages of science and policy are beginning to overlap in the area of outcomes based programs. As Rudolph and Stamm (1999) continue to inform:

Science deals in probabilities . . . answers are greater or lesser statistical support. In policy, answers must be definable, absolute, and unambiguous so that they can be translated into actions. Thus, science must be willing to commit to taking a stand, even if it is based on probabilities, and policy makers must be willing to realize that outcomes are not always predictable. (p. 280)

This compromise should be game on for everyone, and the caregivers must be clear as to what it is they are advocating. Perhaps, gently turning them back onto themselves, I would say these caregivers are best served by putting themselves first, which I understand may feel unnatural, but nonetheless may offer them their best chance of creating an active, more national listening.

A Non-Zero-Sum Game

There is no map for pure creation. Authenticity and genuineness are not commodities for sale or trade. They are created as such. The Elizabeth Dole Foundation knows this. Every woman I spoke with, in her own way, lives this. People are capable and, with opportunity and in partnership with businesses, professionals, and concerned citizens, they will handle the

necessities of their lives. Certainly, caregivers cycle back to the myriad emotions previously discussed in the topical theme of disillusionment, feeling angry, depressed, or depleted. We all do. Life is dynamic, messy, and always unpredictable. But every time a caregiver experiences a debilitating feeling or mood, has a set back and wants to quit but continues to move forward, her resilience and self-confidence build when she recognizes how far she has come (Van Tilburg, personal interview, April 18, 2017).

If our nation is committed to collaboration, if we moved in and met these caregivers right where they are, like a well-executed strike, the awareness of their needs would have the opportunity to scale up. And with awareness comes responsibility. The Dole Foundation has already set the framework for this, and models of care, albeit deeply in need of increased and sustainable funding, are already in existence throughout the United States. There are many established and well-known agencies that care about the future of the military caregiver.

Hidden Heroes Cities. As we move forward, the next step would be to blanket the nation in awareness. More of us, as professionals, administrators, policy makers, and concerned citizens-need to come out from behind the shadows and mobilize together in partnership for a newly created, workable future for our military caregivers. The Dole Foundation has already begun the serious business of raising awareness. According to the Foundation:

During the summer of 2016, the Elizabeth Dole Foundation worked with the U.S. Conference of Mayors to pass an important resolution to encourage cities to increase resources for military and veteran caregivers. To inspire participation, the [Foundation] established Hidden Heroes [Cities], a growing network of cities, counties, and states to better serve our caregivers and share best practices. (“Building Hidden Heroes Cities,” n.d., para. 1)

One of the crucial elements of this resolution in support of military and veteran caregivers is that each city that signs on to become a Hidden Heroes City commits to identifying military and veteran caregivers residing in their respective city, thereby providing for the first

time a mechanism to begin to build an accurate count of these individuals.

Implications for Practice

In reflecting over the time since the introduction to my first Elizabeth Dole Fellow, I have come to believe even more strongly that the more our military caregivers' stories become public, the less room we have as a nation to remain neutral. While we may idolize the warriors from afar and praise them on their return, their illnesses, injuries, or wounds bring incalculable suffering to themselves and everyone associated with them. Long-term, multi-generational effects were clearly articulated as the women spoke of themselves, their children, their extended families and friends, confirming that no one goes unaffected, including our country's larger social body. If the struggles within our society to do right by our military do not focus on post-conflict realities (Everson & Figley, 2011) and the proper care of our military caregivers, we will continue rushing into the strong headwinds of a public health crisis.

The 2014 RAND study created their recommendations organized around four Strategic Objectives:

1. Empower caregivers
2. Create caregiver friendly environments
3. Fill gaps in programs and services to meet needs
4. Plan for the future (p. 133).

Using the framework of the objectives set out by the RAND study, the following implications for practice are presented as additional suggestions.

Change the narrative. Self-identification of caregivers earlier on in the process following traumatic injury or illness would serve to ultimately empower the one giving care. The years it takes for some to self-identify are precious lost years where emotional, physical, and

time-management support could have been offered. It may be time to change the narrative of the use of the term caregiver in some contexts, particularly as we work with younger populations. For example, literature that is available through the VA or in hospital lobbies could be re-linguaged or expanded, reflecting an awareness of the problem with a more relatable term.

Other than medical doctors, the two professions that I have experienced as intervening most frequently with this trauma population, their spouses, and their families in the earlier stages, are nursing and social work. Creating a professional culture grounded in the development of role identity and how we as professionals talk to families, especially spouses, would help frame our conversations more appropriately, resulting in less resistance and more buy-in, especially from the spouses.

The caregiver and the medical team. Most of the women expressed frustration that they were not regarded as having value to bring to the medical team, despite being the ones in charge of their husbands' health and well-being. One woman summed up the general feeling, "It would be nice to go into the VA and be able to speak like someone was listening . . . [what I felt was] oh, here she is. Can you just please sit in the waiting room and look at the magazines?" At all levels that the VA intervenes with the veterans are the same levels within which the system must be intervening with their caregivers. Valuable information is not being communicated that could equally benefit the veteran and his caregiver. We must never underestimate the worth the veteran's caregiver brings to the team.

Helping caregivers begin to understand and relate to their new role more gently earlier on and redefining the role of caregiver in the VA system may be a critical ways to help in everyone's recovery process. These are additional suggestions following RAND's first strategic objective of empowering the caregiver.

Employment. Extrapolating from the stories, the desire to go back to work at the point in most of the narratives, had less to do with re-establishing a personal identity than it had to do with either financial survival or a need “to get out of the house.” The Dole Foundation has begun to encourage partnerships with companies who are willing to hire military spouses and veterans as well, and this is an area that has a significant amount of room to grow. The double bind for the military spouse whose husband is wounded, ill, or injured is she is a caregiver first, not a spouse or a professional, and cannot remove herself from that responsibility. At this point, a viable suggestion would be for businesses to provide more work at home situations. On a much grander scale, it would be interesting to see if businesses would commit to hiring caregiving spouses while also providing socialization centers for the wounded warriors in the same space or in a centralized location. This would allow the spouses quicker access to their husbands in the event of a distress call, while on the other hand, would give the husbands an opportunity for recreation and socialization. Many different opportunities and programs could be included for the veterans, the possibilities of which are endless.

Making small and large changes in the work environment is an additional possibility following RAND’s second strategic objective of creating caregiver friendly environments.

Education. PTSD and TBI are pernicious, the effects of which may take months or even years to be fully revealed. Many women reported having had no information or training in this. One woman said, “We were never told what to expect, that this could even happen.” They did not know what to look for in behavioral changes in their spouses, what to do if they did notice something unusual, or where to go to talk about any worrisome changes. As professionals in the field, I believe we could anticipate this better for the caregivers, for example, by setting up regular, informal electronic chats early on for the wives to start a relationship with a professional

who could provide security for that spouse. One woman said, “It would be nice to have an ongoing connection, no strings attached, just someone to care about how I was doing.” This relationship, built over time, would be a natural segue to drop-in visits to the families, as some way to let the spouses know they are not alone, that someone cares about their success, and who could refer immediately if necessary. The spouses can always use a lifeline, particularly since they are now in civilian communities.

Intimacy and the sexual health and well-being of veterans and their spouses or partners must be opened up for discussion, training, and education. Not all wounds are invisible, and those combat veterans who present with the visible injuries and wounds of war are equally at risk for impaired capacity for intimacy. As one woman said in reference to her husband, “I have four children; well, actually, I have five.” And several mentioned that their husbands “could no longer carry on an adult conversation,” adding to the complexity of the needs of caregivers. Both sides of the dyad need care and nurturing in these sensitive areas if we are to include the range of problems that arise. Once caregivers have secured their place on the medical team along with their wounded, ill, or injured veteran, discussions leading to intimacy and sexual health would be more natural, providing opportunities for the treating staff to hear and listen to not only what the couple is saying but also to hear and listen for what is not being said.

Children. Children were an on-going source of stress for the women. They knew their children were not growing up in “normal” households, yet most were very uncomfortable having the children seen by civilian therapists, believing they would call Child Protective Services without knowing the fact of the matter of PTSD or TBI. Many women did not even realize the extent of the stress their children were carrying.

As addressed in the first chapter, the Dole Foundation has seven Impact Councils to which the Fellows advise: Community Support at Home, Education and Training, Employment and Workplace Support, Financial and Legal Issues, Interfaith Action and Ministry, Mental and Physical Health, and Respite Care. I would add Children as the eighth Impact Council. The children need their own peer-support group(s), camps and retreats, and opportunities to be surrounded by other children in similar home situations. They need therapists who understand the unique circumstances that PTSD and TBI in a parent bring to the home front. Group counseling can be a powerful and effective way to address the children's issues. Ongoing relationships could continue as would any adult relationship, through electronic hangouts and meetups, webinars, and annual retreats.

These are two additional suggestions that could meet the criteria following RAND's third strategic objective of filling in gaps and programs and services to meet needs.

Fear for the future. This final implication for practice was a tremendous stressor for nearly every woman who participated in this study. Their financial futures are precarious, and after having heard a specific, consistent concern articulated across narratives, the way the government looks at military caregiving must change. From a practical perspective, most of the women in this study had very little, if any, money left at the end of the month to put into savings. This unfortunate reality was the result of their husbands' pay grade at the time of discharge, not being able to work any longer, and/or the reduction (or even termination) of stipend reimbursement for their caregiving. Building wealth in today's economy is difficult. The fact that these caregivers cannot pay into Social Security or have some guarantee from the government that they will be financially cared for in the event of the death of their spouse, whether timely or otherwise, is shameful. Many found the stress of this fact to be one of the

most painful facts of their lives. We need people—policymakers, outspoken caregivers and veterans, industry leaders—to pick up the gauntlet and lead the charge in changing the policies around future financial benefits for the caregivers, who the VA relies on to ease the financial strains within their own systems. These caregivers need to be paid what they are worth, at least comparable to caregiving wages in the private sector; and a system needs to be put in place to secure their financial futures.

This is an additional suggestion following RAND’s fourth strategic objective of planning for the future.

Limitations of the Study

Those who apply to become Elizabeth Dole Military Caregiving Fellows are carefully selected, as over a two-year period, they will be representing the Dole Foundation in the work they do to advocate, strengthen, and build awareness in each of their respective states and Puerto Rico. Once appointed, many of these caregivers will then become leaders in their communities, moving agendas at the local, state, and national levels. They will be the voices that lead and champion on behalf of the 5.5 million caregivers who stood to be counted in the 2014 RAND study (Ramchand et al., 2014) and for the thousands more who have joined the ranks since that time. Therefore, my participants were very unique against the backdrop of the millions of military caregivers across the country. They are trained by the Dole Foundation, connected to countless resources, and have a tremendous, ever-expanding peer and professional network within the Fellowship. Collectively, they are a powerful force, atypical of military caregivers. As one Fellow said, “I would hate to be somebody on the other side of the table and have a group of Dole Fellows facing them down.”

Recognizing that caregiving comes in many forms, I chose to only interview wives, married to and living with their combat veteran husbands, and therefore third-person pronouns used in this study are all feminine relating to the wives. One interview was with a Fellow whose husband was a non-combat veteran. However, her narrative was consistent with the 13 other narratives, did not change the analysis, and to honor her and her life's commitment, I included her story in the database. My choice for interviewing wives exclusively was based on the higher number of potential participants that existed within the Dole Foundation. It is further recognized that the children were not included in this study. They continue to represent a highly understudied and underserved population. However, they were not studied as part of a subset to this research as, having worked with young children for decades, I believed their considerations and needs to be uniquely different. In my experience, the children present as an entirely different research study.

The range in time from last deployment home to the final interview conducted in February 2017 was from three years to 13 years. This span of time naturally offered much healing and subsequent wisdom, and the women were articulate and clear in their communication during their interviews. Many had had unique and creative strategies in place for years, and more importantly, knew how to flex strategies to accommodate the changes of living life with a wounded warrior. All of the caregivers were comfortable in recounting their stories and no emotional triggers were experienced. The captured narratives were told from a place of gained maturity and emotional resilience on the healing arc. This study did not focus on when they were first confronted with the past war trauma, where feelings in response to this trauma would presumably be more intense, inarticulate, and unforgiving.

In keeping with the spirit of narrative inquiry, the interviews were not guided by any particular hypothesis, other than the inquiry into the story around when the woman first became aware she had become a caregiver to her combat veteran husband. This allowed each story to unfold around the narrator's own sense making and desire to tell her story in her particular way.

As the researcher who was the co-creator of each woman's story, I did not look at their stories from a clinical perspective, despite what the literature may have revealed about any aspect of the caregiver's role. It was my intention to honor each story as whole and complete as it was shared with me, and I allowed the narratives to flow in the direction led by each Fellow.

Whether in the vignettes used in the plot analysis or as excerpted statements reflecting the thematic analysis, every attempt was made to include as much salient information as possible; however, inclusion of all aspects of the narratives was impossible.

Very little empirical research is available on the stories of America's military caregivers. This was the first narrative inquiry study, as verified by the Dole Foundation, where the stories of the Fellows' lived experiences were recorded and analyzed for research purposes, and therefore, this study should be considered exploratory.

Conclusion

The results of this study show that the human response to a deeply experienced traumatic event has universal elements. Across the stories of 14 very different women in military caregiving roles, all of different ages, living across various parts of the country, there was a rhythmic pattern they each expressed that bound them in their heartache and longing, as well as their determination, resilience, and perseverance. As one Fellow so aptly stated,

It's like we all live in the same cookie-cutter neighborhood, but we just have [different] upgrades . . . With ourselves, and other caregivers that I counsel, everybody has the same underlying issue; it's just each individual person has a few different things with

those issues, and we can usually help figure things out together with the support of each other.

The military caregiver lives against a shattered backdrop that can take years for her to understand, as often this understanding comes in pieces. The combat veteran is held captive by his traumatic experiences that are played out in responses that his wife cannot understand. She is exposed to real time, in the moment action, to which she has no experience, and there are no second takes. Despite living against the trauma from her husband's past, she cannot stop her life if she wants to move herself and her family forward, which every woman successfully did over time, despite the supreme challenges of the family's reintegration back into itself and into a new community.

A significant step each woman took was the acknowledgment of being her husband's caregiver. Saying "yes" to this new identity as his caregiver meant she also had to say "no" to a former self that defined her through her marriage, her work, children, extended family, and her social activities and freedoms. For many, this new definition took time to assimilate and accept. But our brains are equipped to allow for adaptation, as these women learned to adapt by shifting their priorities, their identities, and their marriage. All the women were eventually inspired towards the calling of the Elizabeth Dole Foundation.

Now that I have heard the stories of these women and have been given the privilege to bear witness to their experiences, the idea of a military caregiver being ancillary to her wounded warrior is an even more unacceptable phenomenon in the United States today than I had previously thought. Our nation's awareness needs drastic heightening and I believe, in partnership with us, it is the military caregivers themselves who collectively will have the loudest voice and biggest impact by drawing back the curtains on their stories that cut through us all.

A Look to the Future

I consciously tried to frame this body of work in a positive way. As I wrote, I was constantly reminded of one woman's comment during our interview, "A lot of people exploit the tough stuff and certainly there's a sacrifice to this life. [But] I don't want people to think that's all it is." And she is right. The dark side is only half of the story. It is not all about war. There is love there, too. As much as I want military caregivers to come out from behind the shadows, I wanted at least to bring the reader of this study into the light.

In a new field with little extant literature on America's military caregiver, more questions were raised than answered in my study, as would be expected. For example, I would be curious to re-connect with the 14 Fellows in another five years to continue on with their stories. Many already entered into the study longitudinally (up to 13 years post onset). After completion of their Fellowship and all had the opportunity to settle their training out into the world for several years, it would be a fascinating study to see what they had managed to create and how their stories had changed and expanded.

I am still curious about the children and other relationships of caregiving—mothers, parents, husbands—and believe studies in any one or all of these subsets would yield important information. Husbands in particular are of interest to me, particularly in light of shifts in identity, and how an active duty service husband would take on a caregiving role differently from a civilian husband, if at all? Paoletti (2002) proposes that "caregiving is a gendered practice . . . a central aspect of gender identification" (p. 808). And Eifert et al. (2015) continue:

Many . . . [construct] caregiving as a feminine practice. Caring is not something that the males of the family cannot do or will not do, but the expectation that they will does not exist. This finding suggests that caregiving is closely related to gender identity. (p. 362)

We have no idea in what state our world will be tomorrow, much less in five years' time. Even though the tempo for war-zone deployments has decreased, there are ongoing operations continuing of which the public may not even be aware; and I sadly suspect there will continue to be wounded warriors coming home to their wives who will need information, support, and guidance. They will need a net to catch and hold them. Maybe forever. And for this, I believe many stories over as many years is one way to capture the hearts of the American people so we are not Comeau's (2014) "audience who signed off" (p. 37). We must never forget that in life, we are all players in the same game.

The Context of Grace

Context shapes our perception of the world. And in this world, people want to be seen and known as authors of their own lives. If we hold military caregivers in a context of being weak and vulnerable, we will never see or experience them as anything other than victims of their uncontrolled circumstances. Never as masters of their own universe.

I held these women, the Dole Fellows within a context that I called grace. And I defined grace as the capacity to see and be with things just as they are, without needing to define, justify, or apologize for anything. Grace, then, was revealed as each woman moved forward authentically and at will with the truth of the matter.

Everything that arose within this context—her grief, heartache, anger, regrets, all of her vulnerabilities and weaknesses, as well as her joy, laughter, successes, and hopes—all of it was a contribution to her strength and spirit as she moved forward in this empowered state of grace.

Appendices

Appendix A: Copyright Permission

Permission to reprint in this dissertation four poems by Melissa Comeau:

The heroes don't look the way they used to— p. 3

No two hearts work harder—p. 18

Why do you stay?—p. 62

This story is as camouflaged—p. 131

These poems all appear in:

Comeau, M. (2014). *Sleeping with the war*. Parker, CO: The War Writers' Campaign, Inc.

The copyright for these poems is held by the War Writers' Campaign, Inc.

The permission is from Ryan Weemer, the Co-Founder and CEO. The August 4, 2017, email from Ryan Weemer gives permission to make edits to the poem by changing the word too to the word to.

Melissa Comeau is a poet, writer, and the author of *Sleeping With the War*. She is the Director of the Red Cross Military Veteran Caregiver Network that offers peer support and services, linking caregivers to an online peer support community, peer-mentor support programs, and online and community-based peer support groups. And she has also been a Fellow alumni of the Elizabeth Dole Foundation since 2015.

A very special thanks is extended to Melissa and her publisher, Ryan Weemer, Co-founder and CEO of the War Writers' Campaign, Inc., both of whom allowed use of her poems in this dissertation.

From: **Jennifer Hunter** <jhunter1@antioch.edu>
 Date: Fri, Aug 4, 2017 at 6:29 PM
 Subject: Re: Asking permission to reformat a word
 To: War Writers Campaign <ryan@warwriterscampaign.org>

Thank you Ryan, so much!

Take care, Jennifer

On Fri, Aug 4, 2017 at 6:19 PM, War Writers Campaign <ryan@warwriterscampaign.org> wrote:
 Jennifer,

You have my permission to make the necessary edits to Melissa's work for your publication.

All the best!

Ryan Weemer

Co-Founder/CEO
 The War Writers' Campaign, Inc.

On Aug 1, 2017, at 12:56 PM, Jennifer Hunter <jhunter1@antioch.edu> wrote:

Hi Ryan -

I had not realized this until just now. The poem by Melissa entitled "**The heroes don't look the way they used too**" has a typo that I need your permission to change.

The word "too" at the end of this line and also on the 4th line in the poem, should instead read "to" > "The heroes don't look the way they used to"

This is the first line on the first page of my dissertation. May I have your permission to change "too > to" ?

If you give me permission, please just state as such in a reply email to me and I will include your agreement in my permissions page.

Thank you so much, Ryan! I appreciate your help on this. If we can add this change, then the work is getting very close to publication.

Sincerely, Jennifer Hunter

On Sun, May 14, 2017 at 11:27 AM, Jennifer Hunter <jhunter1@antioch.edu> wrote:
Dear Ryan –

I am a doctoral student at Antioch University, writing a dissertation entitled “Revealing Grace: A Narrative Inquiry into the Lived Experiences of America’s Post-9/11 Military Caregivers.”

I am requesting permission to use four (4) of Melissa Comeau’s poems from her book of poetry titled *Sleeping with the War*. Attached to this email, please find the poems I would like to copy and how I will be referencing her work.

This dissertation will appear in these three archives:

- a. Proquest Dissertations and Theses Database and that Proquest is a Print on Demand Publisher <http://www.proquest.com/products-services/pqdt.html>
- b. Ohiolink Electronic Theses and Dissertations Center and that Ohiolink ETD Center is an open access archive <https://etd.ohiolink.edu/>
- c. AURA: Antioch University Repository and Archive and that AURA is an open access archive. <http://aura.antioch.edu/>

If you agree to this, please give me your permission via reply email.

Thank you very much, Ryan. I appreciate all your help.

Sincerely,

Jennifer Hunter

From: **Ryan Weemer** <ryan@warwriterscampaign.org>
Date: Wed, May 24, 2017 at 7:08 PM
Subject: Re: Antioch University Formal Request for Use
To: Jennifer Hunter <jhunter1@antioch.edu>

Hello Jennifer,

This is a great endeavor and we're proud we can be a part of your work! We agree and give permission for you to use Melissa Comeau's work. References look good, thanks again!

Best of luck!

Appendix B: Informed Consent and Demographic Questionnaire

INFORMED CONSENT FORM

This Informed Consent Form is for current and past Elizabeth Dole Fellows who are caregiving wives living with their combat veteran husbands who served in a post-9/11 combat theater of war (Iraq or Afghanistan).

We are inviting you, the Elizabeth Dole Fellow, to participate in a research project titled “The Healing Fields: A Narrative Inquiry Into the Lived Experiences of America’s Military Caregivers”

Name of Principle Investigator: Jennifer Hunter

Name of Organization: Antioch University, PhD in Leadership and Change Program

Name of Project: The Healing Fields: A Narrative Inquiry Into the Lived Experiences of America’s Military Caregivers

You will be given a copy of the full Informed Consent Form

Introduction

My name is Jennifer Hunter, and I am a PhD candidate in the Graduate School of Leadership and Change at Antioch University. As part of this degree, I am completing a project to study the lived experiences of post-9/11 military caregiving wives who have been or are currently appointed as an Elizabeth Dole Fellow. I am going to give you information about the study and invite you to be part of this research. You may talk to anyone you feel comfortable talking with about the research, and take time to reflect on whether you would like to participate or not. You may ask questions at any time.

Purpose of the research

The purpose of this project is to provide a place for your voice where we can hear, learn from, and give honor to your story through the qualitative methodology of narrative inquiry. This information may help us to better understand how you have made sense of your experience and how your sense making can be woven into practices and policies to further support the groundwork needed to direct a national response and call to action. Although Elizabeth Dole Fellows have been specifically chosen for this study, reestablishing a sense of order and connection is an important outcome for the narratives of all military caregivers when faced with a traumatic disruption in life. Through the narratives of the Fellows, I trust that a holistic picture will emerge as an authentic representation of all military caregivers.

Type of Research Intervention

This research will involve your participation in a tape-recorded telephone interview. During this interview, you will be asked to share your story. For those within geographical proximity, personal interviews are an option if appropriate. Questions may be used to stimulate topic discussion. Each of these interviews will be tape-recorded solely for research purposes. Initial interviews should last approximately 60 minutes, with the possibility of briefer follow-up contact when necessary. The interviews will be conducted at a time and day that accommodates your schedule. Prior to any contact, you will be emailed an Informed Consent Form that has been approved by Antioch University’s Institutional Review Board and the Elizabeth Dole Foundation, along with a brief demographic questionnaire that will allow us to move more quickly into the interview.

All of the participants’ contributions will be de-identified (pseudonyms will be given to each participant and her husband) prior to publication or the sharing of the research results. These audio recordings, and any other information that may connect you to the study, will be kept in a locked, secure location.

Participant Selection

You are being invited to take part in this research because you are an Elizabeth Dole Fellow who is currently serving or has served as a Fellow. Your combat veteran husband has served in a post-9/11 combat theater of war (Iraq or Afghanistan) and you are currently in a position of needing to give care to him. You should not consider participation in this research if you do not meet this criterion.

Voluntary Participation

Your participation in this study is completely voluntary. You may choose not to participate. You will not be penalized for your decision not to participate or for any of your contributions during the study. **Your position as an Elizabeth Dole Fellow will not be affected by your decision to participate or not.** You may withdraw from this study at any time. If an interview has already taken place, the information you provided will not be used in the research study.

Risks

No study is completely risk-free. However, I do not anticipate that you will be harmed or distressed during this study. You may stop being in the study at any time if you become uncomfortable. If you experience any discomfort as a result of your participation, employee assistance counselors will be available to you as a resource.

Benefits

There will be no direct benefit to you, but your participation may help others in the future.

Reimbursements

You will not be provided any monetary incentive to take part in this research project.

Confidentiality

All information will be de-identified, so that it cannot be connected back to you. Your real name and that of your husband will be replaced with pseudonyms in the write-up of this project, and only the primary researcher will have access to the list connecting your names to the pseudonyms. This list, along with tape recordings of the discussion sessions, will be kept in a secure, locked location.

Limits of Privacy Confidentiality

Generally speaking, I can assure you that I will keep private everything you tell me or do for the study. Yet there are times where I cannot keep things private (confidential). As the researcher, I cannot keep things private (confidential) when:

- The researcher finds out that a child or vulnerable adult has been abused
- The researcher finds out that a person plans to hurt him or herself, such as commit suicide
- The researcher finds out that a person plans to hurt someone else

There are laws that require many professionals to take action if they think a person is at risk for harm or is self-harming, harming another, or if a child or adult is being abused. In addition, there are guidelines that researchers must follow to make sure all people are treated with respect and kept safe. In most states, there is a government agency that must be told if someone is being abused or plans to self-harm or harm another person. Please ask any questions you may have about this issue before agreeing to be in the study. It is important that you do not feel betrayed if it turns out that the researcher cannot keep some things private.

Future Publication

The primary researcher, Jennifer Hunter, reserves the right to include any results of this study in future scholarly presentations and/or publications. All information will be de-identified prior to publication.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and you may withdraw from the study at any time.

Who to Contact

If you have any questions, you may ask them at any time. If you have questions later, you may always contact me, Jennifer Hunter, at jhunter1@antioch.edu

If you have any ethical concerns about this study, please contact **Lisa Kreeger, Chair, Institutional Review Board, Antioch University Ph.D. in Leadership and Change, Email: lkreeger@antioch.edu.**

This proposal has been reviewed and approved by the Antioch International Review Board (IRB), which is a committee whose task it is to make sure that research participants are protected. If you wish to find out more about the IRB, please contact Dr. Lisa Kreeger.

DO YOU WISH TO BE IN THIS STUDY?

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant _____

Signature of Participant

Date _____
Day/month/year

I voluntarily agree to let the researcher audiotape me for this study. I agree to allow the use of my recordings as described in this form.

Print Name of Participant _____

Signature of Participant

Date _____
Day/month/year

To be filled out by the researcher or the person taking consent:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____
Day/month/year

Demographic Questionnaire

Participant

First name:

Preferred pseudonym for yourself:

Years you served (are serving) as a Dole Fellow:

Best contact phone number (and best time to contact):

Email address:

City of residence and time zone:

Number of years married:

Number and ages of children:

Do any of your children have special needs?

How many people in total are living in your household?

Is there a family tradition of being in the military? If yes, please briefly describe.

Are you currently serving in the military?

If so, for how long?

What is your current rank?

Date(s) and length(s) of any deployments

Do you currently work outside of the home?

If so, how many hours per week?

How long have you been employed outside of the home?

In what field do you work?

What is your highest level of formal education?

On average, approximately how many hours a week are you in a caregiving role to your husband?

What (if any) formal caregiving training have you had:

Spouse

Preferred pseudonym for your spouse:

In what branch of the military did your husband serve?

What were the years of his service and official discharge date?

What was his rank upon discharge?

How many deployments did your husband have?

For approximately what length of time was each deployment?

Nature of husband's wound(s) or injury(ies) and/or disability(ies) upon military discharge

When and where did this/these occur?

What is his highest level of education?

Does he currently work outside of the home?

If so, how many hours per week?

And in what capacity?

Appendix C: Transcript of the Author's MP4 Video Introduction

Hi. My name is Jennifer Hunter and I have completed a dissertation titled *Revealing Grace: The Lived Experiences of America's Post/9-11 Military Caregivers*.

This was a qualitative study, using Narrative Inquiry and the stories of 14 Elizabeth Dole Military Caregiving Fellows, all wives living with and giving care to their post-9/11 combat military veteran husbands.

These stories as data were analyzed using both a plot analysis as well as a thematic analysis.

It was within the deep structure of the narratives connected to the thematic roadmap, that a holistic picture emerged of the wives' journeys.

But most importantly, it is through their stories that we are reminded of our universal connection, and the joy and suffering that cut through the hearts of us all.

Thank you for your interest. Please feel free to reach out any time.

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