Title

Cardiovascular Health in the Mothers and Wives Caring for Veterans with Traumatic Brain Injury or Post Traumatic Stress Disorder

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Cardiovascular Health in the Mothers and Wives Caring for Veterans With Traumatic Brain Injury or Post Traumatic Stress Disorder

A dissertation in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing

by

Judith Lynn McKelvy

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ABSTRACTOF THE DISSERTATION

Cardiovascular Health in the
Mothers and Wives Caring for Veterans
with Traumatic Brain Injury or Post Traumatic Stress Disorder

by

Judith Lynn McKelvy
Doctor of Philosophy in Nursing
University of California, Los Angeles, 2019
Professor Lynn Doering, Chair

Background: Family caregivers are the cornerstone of support for our nation's wounded. While caregiver burden has been studied extensively in caregivers of patients with dementia, stroke, and cancer, little is known about the burden of caregiving in the context of service-related injuries like traumatic brain injury(TBI) and Post Traumatic Stress Disorder (PTSD). Studies have shown that depression, anxiety, and caregiver strain are associated with lifestyle risk factors for coronary heart disease (CHD).

Purpose: The purpose of this descriptive study was to examine the effects of caregiving on cardiovascular health in mothers and wives caring for veterans with invisible wounds of war.

Methods: The study utilized a sequential, exploratory, mixed method design with convergent results. Participants completed an online survey. Analysis included descriptive and correlational statistics. The qualitative interviews used a semi-structured interview guide that explored the daily experience of the caregiver and facilitators and inhibitors to heart health self-care. The interviews were transcribed and coded and content analysis was conducted.

Results: Caregivers reported spending the greatest amount of time providing emotional support for the veteran and managing behavioral problems. Neurobehavioral symptoms most frequently reported by caregiver as being severe included forgetfulness and anxiousness. Many caregivers demonstrated anxiety that would be classified as needing further evaluation and depressive symptoms consistent with major depression. Overall, poorer heart health was correlated with higher scores for depressive symptoms and perceived stress. Thematic content analysis was used to identify seven major themes: (1) Neurobehavioral Symptoms: Managing the Unpredictable; (2) Home as the Safe Place; (3) VA Healthcare System: Fighting to Navigate a Complex System (4) Self-Care: Finding Time to Care for Self; (5) Caregiver Peers: Creating a New Community (6) Post Traumatic Growth: Learning to Become a PTSD Expert; (7) Motivation: Sacrificial, Unconditional Love

Conclusions: Results of this study will be used to design a health promotion intervention for caregivers utilizing principles of community based participatory research and trauma informed care.

The dissertation of Judith Lynn McKelvy is approved.

Eunice Eunkyung Lee

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2019

DEDICATION

In memory of my parents, Judy and Frank Foley and my husband George McKelvy. “Greater love has no one than this, that one lay down his life for his friends (John15:13). My parents and my husband loved these words. My father modeled the Marine Corps values of honor, courage, and commitment. It is the inner strength that enables the Marine to take the extra step. My husband modeled the seven Army values of loyalty, duty, respect, selfless service, honor, integrity, and personal courage. Their love and support enabled me to keep taking that next step, advancing in my profession and completing this dissertation.

A special word of gratitude goes to my Mom. “Older women are to be reverent in their behavior... to be sensible, pure workers in the home, kind, being subject to their own husbands, so that the word of God will not be dishonored” (Titus 2:3,5). My Mom was a Titus 2 woman. Not only did she faithfully and lovingly care for a veteran with invisible wounds of war, she believed her daughter was entitled to the same quality education as her brothers. She modeled the values of sacrifice and selfless service and was an example of a true “hidden hero”. This dissertation is dedicated to her and the millions of other “hidden heroes” caring for our nations’ wounded.

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Chapter 1

Introduction

“To care for those who shall have born the battle and for the widow and his orphan…” This is the commitment that President Abraham Lincoln made on behalf of the American people to care for veterans of military service. The United States has been at war longer than any time in its history.[1] Thousands have been wounded in this long running conflict requiring long-term caregiving support. This care is often left to the family and friends of the wounded.

Since September 11, 2001, over 2.7 million Americans have served in the conflicts in Iraq and Afghanistan.[2] Changes in military operations including more frequent deployments have influence the rates of mental health conditions and cognitive impairment. Post traumatic Stress Disorder (PTSD) and traumatic brain injury (TBI) have been labeled the “invisible wounds” of modern warfare. The psychological wounds of warfare are nothing new, the risk for mental health conditions are greatest during war and conflicts. [1,3] The use of improvised explosive devices (IED) by the enemy have made blast-related TBI, particularly mild TBI, the “signature wound” of the current conflicts.[4] Of soldiers wounded in Iraq and Afghanistan, 22% have sustained injuries to the face, head, or neck which roughly estimates the incidence of TBI.[4] Advances in body armor technology and acute care have led to an increase survival rate among servicemembers.[4] Persistent post concussive symptoms, TBI, and PTSD in these veterans may lead to long term health effects and resultant lifelong caregiving needs. [3,5,6] It is estimated that 1.1 million caregivers are caring for a person who served post 9/11.[7]

Caring for a family member with a disability is known to cause chronic stress, which is associated with negative physical and emotional health consequences especially when resources for caregiving are not sufficient.[8,9] In the landmark Caregiver Health Effects Study, participants providing care and experiencing strain had mortality risks 63% higher than those of non-caregiving controls.[10] Three out of four caregivers in the United States are women. Female caregivers are more likely than male caregivers to reduce their work hours or leave the labor force.[11,12] In a study examining barriers to cardiovascular health, 42% of women reported that family obligations and caring for others was an impediment to heart health.[13] Overall, women tend to experience the greatest emotional stress, which puts them at risk for poor physical health themselves.[14] Female caregivers experience higher levels of depression and anxiety than male caregivers.[15] Depression is a risk factor for coronary heart disease (CHD) in both healthy adults and dementia caregivers.[16]

While caregiver burden has been studied extensively in caregivers of elderly and chronically ill patients, little is known about the burden of caregiving in the context of service-related injuries like TBI and PTSD.[7,8] Family caregivers are the cornerstone of support for our nation's wounded. These caregivers have unique challenges functioning as case managers, advocate for new treatments for the veteran, and provide financial and legal representation. These caregivers often sacrifice their own health and emotional well-being to care for the veteran.[17] These multiple responsibilities effect caregivers health with military caregivers reporting increase prevalence of stress and anxiety, sleep deprivation, poor eating habits, less time exercising, and skipping doctors' appointments.[17]

The FACES study was the first study to examine the experience of caring for veterans with TBI suffered in Iraq and Afghanistan. In this study 30% of caregivers spent more than 20 hours per week caring for the veteran.[5] Caregiving nine hours or more per week was associated with an increased risk for CHD.[18] The Rand Corporation completed a study examining the needs of military caregivers and found that post 9/11 caregivers differ from other caregivers as they are younger, employed, not connected to a support group, and more likely to use mental health resources. In this study 40% of post 9/11 caregivers met the criteria for probable depression. Post 9/11 caregivers performed fewer activities of daily living (ADL) and instrumental activities of daily living (IADL) than other caregivers but spent more time assisting the veteran in coping with stressful situations and other emotional and behavioral challenges. [7]

Research has focused on the needs of returning service members but the needs of caregivers remains largely overlooked.[17] Studies to date have focused on the psychosocial aspects of caregiver burden.[15] Research examining physical health outcomes, in particular, cardiovascular risk, is limited.[19]

The overall purpose of this descriptive, exploratory, mixed method study is to examine the effects of caregiving on cardiovascular health in female caregivers of post 9/11 veterans with invisible wounds of war. Specific aims of the quantitative study include:

1. Describe the severity of emotional burden and practical burden in female caregivers of veterans with TBI or PTSD.
2. Describe the correlation of caregiver burden to the type of neurobehavioral symptoms (somatic, affective, or cognitive) in veterans with TBI or PTSD. *Hypothesis:* *Caregiver burden will be more highly correlated to veterans' affective symptoms compared to cognitive or somatic/sensory symptoms.*
3. Explore the relationship of psychobehavioral caregiver variables to cardiovascular health in female caregivers of veterans with TBI or PTSD. *Hypothesis:* *Caregiver emotional burden, practical burden, perceived stress, depression, anxiety, and social support will be correlated with poor cardiovascular health.*

The specific aims for the qualitative study include:

4. Explore the experience of caregivers of veterans with invisible wounds of war as related to cardiovascular health.
5. Identify the barriers and facilitators of heart health self-care as perceived by the caregiver.

Implications:

The family caregiver is instrumental in allowing the veteran to stay at home and in the community. By identifying caregivers at risk for cardiovascular disease, researchers can design interventional studies that foster health promotion and support caregivers in their role. As women have been identified as “heart keepers” of the family, promoting cardiovascular health in women should lead to improved health for the veteran.[13]

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Chapter 2

Review of the Literature

Over thirty-five years ago, researchers predicted that the movement of women into the workplace and their resultant combination of roles as wives, mothers, and wage earners would be accompanied by added stress. Further, researchers posited that added stress would cause women to lose their survival advantage over men and could increase their mortality rates from chronic diseases, such as coronary heart disease.[1] Today, this prediction has proven to be accurate – heart disease, the number 1 killer of women, claims 422,000 female lives each year.[2] Besides working outside the home, women are assuming in greater numbers the role of family caregiver to disabled adults.[3] Caregiving responsibilities have been cited as an impediment to heart health.[4]

As increasing numbers of veterans return from combat in Iraq and Afghanistan, traumatic brain injury (TBI) is being recognized as a significant source of disability among veterans. Women, primarily wives and mothers, are the primary caregivers of veterans with TBI. They are instrumental in assisting veterans' return to the civilian community. These women sacrifice their own physical and emotional health, putting their own concerns behind the needs of the veteran.[5] This review of the literature will include discussion of: 1) current state of the science regarding the neurobehavioral effects and long term sequelae of blast-related TBI in veterans; 2) TBI caregiver characteristics and psycho-behavioral responses; 3) the physical and psychological health consequences of caregiving in general; and 4) current knowledge of determinants of caregiver stress, the psychobehavioral response to caregiving demands and subsequent impact on cardiovascular health outcomes. Table 2.1 presents a summary of government and private foundation reports pertaining to TBI and family caregiving in veterans.

I. Neurobehavioral Effects of Blast-Related TBI in Veterans

Since September 11, 2001, 2.4 million Americans have served in the conflicts in Iraq and Afghanistan.[6] Traumatic brain injury (TBI) has been a major cause of morbidity and mortality due to the enemy's reliance on improvised explosive devices (IEDs). Initially, the research focused on moderate to severe TBIs recognized in theatre. However, as veterans returned home they were presenting to the Veteran Affairs (VA) hospitals with symptoms suggestive of the residual effects of mild TBI that were not diagnosed before discharge from the military.[7] This section of the literature review will discuss the incidence, diagnosis, comorbidities, and long term outcomes for veterans with TBI. Table 2.2 presents a summary of relevant traumatic brain injury studies and their strengths and weaknesses.

Advances in body armor technology and acute trauma care have allowed many service members to survive injuries that may have been fatal in previous wars. Kevlar body armor and helmets are one of the reasons for the high proportion of TBI among soldiers wounded in current conflicts. These helmets have reduced the frequency of penetrating head injuries but they cannot protect the face, head, & neck, resulting in a higher proportion of head and neck injuries.[8,9] Traumatic brain injury has been labeled the "signature wound" of the Iraq and Afghanistan conflicts. According to one study, 22% of soldiers wounded in combat in Iraq and Afghanistan, have sustained injuries to the face, head, or neck which can serve as a rough estimate of the incidence of TBI.[8]

A. Incidence and Diagnosis

From 2000-2013, the Department of Defense has identified 280,734 cases of TBI with the majority of cases being classified as mild TBI (82.4% or 231,386 cases).[10] Penetrating brain injuries are readily identifiable, but mild to moderate brain injuries are more difficult to diagnose.[11] Clinical assessment of closed head injury must rely on objective evaluations of altered consciousness, cognition, and behavior, and where available, neuroimaging.[12,13] Often, TBI symptoms are not apparent until soldiers have been out of the war zone for several months, at which point they come home and are unable to function or experience personality changes.[8,12,14] Because the diagnosis of mTBI is easily missed, the Department of Veterans Affairs has initiated a four-question post deployment TBI screening process for all veterans. Veterans with a positive screen are referred for further neuropsychological evaluation, including the 22 item Neurobehavioral Symptom Inventory.[15,16] In diagnosing mTBI, researchers continue to examine the usefulness of neuroimaging methods, such as diffusion tensor imaging (DTI), and biomarkers, such as S110B, glial fibrillary acidic protein (GFAP), and ApoE4.[17-19] Figure 2.1 presents a summary of characteristics of TBI and prevalence and diagnosis of comorbidities.

B. Comorbidities and Mild TBI

Another challenge in identifying and treating TBI among returning service-members is that many symptoms such as anger, sleep disturbance, or difficulty concentrating are characteristic of comorbid conditions such as post-traumatic stress disorder (PTSD) and depression.[11,14,20] Veterans with confirmed TBI may also have comorbid PTSD and/or depression.[21-25] In a study that examined mental health diagnoses of veterans using Department of Veterans Affair Health Care from 2002-2008, investigators found that 21.8% of veterans from Iraq and Afghanistan were diagnosed with PTSD and 17.4% of veterans were diagnosed with depression.[26] Veterans with positive TBI screens were twice as likely to screen positive for PTSD and depression.[25] Also, mTBI has also been associated with visual imperceptions and impaired tandem gait.[27]

Although most symptoms of mTBI resolve within a few months, several problems (i.e., depression, aggression, and post-concussive symptoms such as memory problems, irritability, and dizziness) may last for years.[14,15,27,28] It is estimated that persistent post-concussion symptoms will be observed in 5-15% of mTBI cases.[29,30] Comorbid TBI and PTSD result in greater reports of post-concussive symptomology than either condition alone.[31,32] There is intense controversy regarding whether post-concussive symptoms reported by veterans from

Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) are indicative of structural or functional brain damage or whether they are due to psychological trauma.[33] A number or researchers have found a strong association between post-concussive symptoms and PTSD.[22,28,34] Neuroimaging studies have demonstrated that veterans with mTBI and post-concussive syndrome may have loss of white matter integrity or regional brain hypometabolism. These changes are not seen in subjects with PTSD or depression in the absence of mTBI.[18,33] One researcher recommends that post-concussive symptoms should not be solely attributed to psychiatric disorders until the contribution of structural brain injury has been evaluated.[7]

Veterans returning from Iraq and Afghanistan frequently report symptoms of chronic pain, particularly in the head and back which can be a long term problem.[35] A history of mTBI with loss of consciousness predicted headache pain.[36] In returning veterans, headaches in mTBI were more likely to be classified as migraine.[37] Veterans with three or more concussions (mTBI) were significantly more likely to report headache as well as memory problems, poorer neuropsychological test performance, and slower recovery.[24,38]

Studies in the civilian population have also found that recurrent concussions can have a cumulative effect on memory and recovery.[39,40] Veterans with mTBI are also at risk for recurrent mTBI from falls and motor vehicle accidents once they return to the civilian population.[41]

The impact of mTBI is magnified by the complexity of symptoms that persist over time. In the chronic phase of mTBI (i.e. 5-10 years postinjury) veterans report increased rates of headaches, sleep problems, and memory difficulties. Mild TBI can complicate or prolong recovery from preexisting or comorbid conditions such as PTSD or amputation.[42,43] To date, there has been insufficient evidence to determine an association between mTBI and long term adverse social functioning.[14] One study of Vietnam veterans found that the mTBI group was more likely to report disability, underemployment, low income and marital problems.[27] Future studies will need to examine the long term effects of mTBI on social relations, employment status and quality of life.[14]

C. Summary

Research on mTBI is in its infancy. There is sufficient evidence of an association between postconcussive symptoms and persistent headache in cases of mTBI. There is sufficient evidence of a substantial overlap in the symptoms of mTBI, PTSD, and depression. While researchers debate the neurogenic or psychogenic origin of these symptoms, the family caregiver is responsible for managing these symptoms without the benefit of evidence-based interventions.[44] To date; there have no nursing studies examining best practices of the care of the veteran in the home setting. Nurse researchers first need to conduct descriptive studies in order to develop the foundation for intervention studies.

II. Traumatic Brain Injury Caregivers

Research regarding TBI has focused on the needs of returning service members, but the needs of their caregivers remain largely overlooked.[5] A study conducted by the National Alliance for Caregiving (NAC) examining the needs of caregivers of veterans from combat eras dating from World War II to the present conflicts in Iraq and Afghanistan found that almost three in ten (29%) caregivers say their veteran has had a TBI.[45] Caregivers of veterans are unique in that they tend to be younger women dealing with unique veteran variables related to the veterans' battlefield-inflicted wounds, including mTBI and PTSD. Cognitive and mental injuries, which account for these variables, have been labeled "invisible" wounds and can be just as debilitating as physical injuries.

Caregivers of veterans perform a wide variety of roles and functions in support of their loved ones, including maintaining and managing the veteran's health, identifying and coordinating professional care, providing mental and emotional support for their veteran, and providing legal and financial assistance. Most caregivers balance all these responsibilities while advocating for the veteran within the complex Veterans Affairs Healthcare System.[5] This section will review the literature regarding caregivers of patients with TBI. It will focus on studies addressing the physical, psychological, and social effects of caregiving in both the civilian and veteran populations. Table 2.3 presents a summary of relevant studies related to TBI caregiver research and their strengths and weaknesses.

A. Civilian Literature

1. Mental and Emotional Distress. The topic of psychological distress in caregivers of individuals with TBI has been well documented in the literature over the last four decades.[46] Depression, anxiety and somatic symptoms are common among caregivers, with studies finding the incidence of caregivers demonstrating symptoms of depression ranging from 20%-73%; the incidence of anxiety ranging from 20%-55%; and approximately 20% suffering somatic symptoms.[47-51] Symptoms of psychological distress or stress in caregivers can persist for 10-15 years after the original injury.[46,52,53]

Most of these studies have examined caregivers of individuals with severe brain injured. In these studies, caregiver stress was not affected by the care recipient's severity of illness, however, it was mediated by behavioral and personality changes and associated disability in the care recipient.[52,54-56] Higher stress has been found in caregivers who are caring for individuals with poorer function and in need of greater supervision.[51] Caregiver distress increased with longer elapsed time from the care recipient's initial injury, higher degree of cognitive dysfunction, and unawareness of deficit in the care recipient.[57] In care recipients with TBI, caregiver stress has been related to specific care-recipient neurobehavioral symptoms, including depression, inappropriate behavior, pragnosia, indifference, and emotional withdrawal, fatigue, and memory problems. [53,58] Not all families are affected by TBI in the same way; one study found that differences in perception of problems between the recipient and caregiver add to caregiver distress. In this study, recipients reported problems with executive functioning (i.e., difficulties in planning, organizing, and following through with tasks). However, caregivers were distressed with personality changes, mood swings, temper, arguing with others, and complaining.[59] Several studies found aggression in the recipient to be a significant factor associated with strain in the caregiver. One study found that when personality changes and threats of violence increase markedly by the 5-year mark after the initial injury, caregivers reported becoming afraid of the recipient.[49,52,60]

2. ***Health Deterioration***. Few studies have examined the effects of caring for a family member with TBI on the caregiver's health. Caregivers' medical and psychiatric history predicted caregiver distress and perceived burden following TBI.[56] In France, caregiver health was found to be lower than the general population.[61] Self-reported caregiver physical symptoms were significantly predictive of caregiver depression regardless of the length of time caregiving.[62] Another study reported that 25% of caregivers reported an illness in the preceding 6 months including asthma, migraine, and duodenal ulcer.[63]

3. ***Isolation****.* Perceived social support is highly related to perceptions of burden.[57,64-66] Perceived social support is one of the strongest factors in satisfaction with caregiving.[64] Among caregivers without adequate social support, increased distressed was positively correlated with time elapsed since initial injury, and caring for individuals with impaired executive functioning and poor awareness of their deficits.[57] Perceived social support can protect caregivers from higher levels of stress but if the need for social support is unmet, caregivers feel misunderstood and isolated.[65,66]

3. ***Loss of Income****.* Household income has been related to perceived burden.[67-69] Higher household income is related to lower perceived burden.[68] Caregivers that give up some of their activities or make financial sacrifices in order to care for a relative are more depressed.[68] A significant number of caregivers have to altered or given up their jobs in order to care for the veteran with TBI.[69,70]

4. ***Characteristics of Caregiver***. Perceptions of burden can differ dependent upon the caregivers' age, gender, kinship to patient, or ideology regarding caregiving. Several studies have reported that spouses are more depressed than parents when caring for a person with TBI, and burden is greater on female spouses compared to male spouses.[46-48,55,71] In a qualitative study, one theme expressed by spousal caregivers of persons with TBI was the enigmatic nature of TBI. Spousal caregivers expressed their experience that TBI is difficult to understand and therefore other people do not understand or support the caregiver.[72] These feelings of burden cause the spouse to feel isolated and trapped in the situation, even in cases of mTBI.[47] Although race/ethnicity is not predictive of distress, in Black/Hispanic caregivers, a traditional caregiver ideology was associated with increased distress. The authors hypothesize that the greater sense of obligation and familial duty may result in caregivers' assuming increased responsibility, which results in greater distress. Younger caregivers reported that fewer of their own needs were met, which may explain their greater perceived burden. [73]

B. Veteran Literature

1. Emotional health. As in the civilian literature, studies of caregivers of veterans with TBI have focused on the emotional and psychological impact of caregiving. Neurobehavioral symptoms in the care recipient cause the greatest distress and strain in the caregiver.[74,75] Wives of severely brain injured veterans reported more symptoms of depression than wives of paraplegics or non-injured controls.[63] Wives of war veterans suffering from post-concussion syndrome demonstrated higher levels of emotional burden than wives of veterans with PTSD or healthy controls.[76] In one study, 30% of wives considered divorce and more than half reported feelings of depression, anger, decreased time for themselves and financial insecurity.[75] Wives of brain injured veterans more than wives of paraplegics felt that they assumed the man's role in the family.[63]

2. Caregiver Health. Only one study examined the effects of caregiving on health. Caregivers of veterans with TBI reported less time exercising, weight gain or loss, poor eating habits, and skipping doctor appointments. Over a third of TBI caregivers reported generally getting sick more often.[45] These studies have included veterans from World War II to the present conflicts.

3. Caregivers of veterans of Current Conflicts. Researchers are now focusing on the caregivers of OEF/OIF. A larger number of these veterans are suffering from blast related injuries.[8] The Family and Caregiver Experience Study (FACES) was the first to describe the experience of caregivers of service members with TBI after discharge from an acute polytrauma rehabilitation unit. After a median 4 years since injury, caregivers continued to provide assistance with either activities of daily living or instrumental activities of living as well as helping the care recipient manage emotional issues and navigate the health care system. A majority of caregivers (55%) needed to balance work and caregiving.[77]

Previous studies have shown that neurobehavioral problems like difficulty in communicating, poor impulse control, and poor emotion regulation predict caregiver strain.[58,74] Perceived stigma associated with caregiving was associated with caregiver strain, social isolation, depression, and anxiety in caregivers of veterans who served in Iraq and Afghanistan.[78] In this population, a psychoeducational intervention reduced feelings of isolation, restored relations through communication, and helped caregivers understand the interconnection between TBI and PTSD.[79]

C. Summary

The majority of these studies have examined the effects of caring for a severely brain injured individual. Caregivers report symptoms of depression, anxiety, isolation, and financial strain indicative of significant caregiver burden and stress. Although research on effective interventions have been limited, education based interventions providing education, family support, and skills training have proven to decrease caregiver depression.[62,80] Future studies will need to examine the biopsychosocial needs of caregivers of veterans with TBI and the long term effects on the caregivers' health.

III. Health Consequences of Caregiving

Previously healthy spouses often find themselves developing a variety of physical and mental health problems within 2 years of the onset of an illness or injury in the family. In fact, this pattern has been so frequently documented that spouse caregivers have been called "the hidden patient".[81] Researchers are beginning to ask the question: "Is caregiving hazardous to one's health?"[82] Few studies have been done in this area. This section will review the literature examining physical and psychological health effects of caregiving in women. Table 2.4 presents a summary of relevant studies regarding caregiver health and their strengths and weaknesses.

A. Mortality and Physical Health Effects

Caregiver health effects have been studied extensively in caregivers for elderly patients with disabilities. Researchers in the landmark Caregiver Health Effects study found that being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers.[83]

Several studies have found that caregivers have poorer physical health than non-caregivers as measured by biological sampling of stress hormone or antibody levels or self-report of health status.[82,84-86] Caregivers had higher levels of stress hormones than non-caregivers putting them at risk for hypertension and diabetes.[82] Caregivers also demonstrated poorer antibody production, poorer proliferative responses to mitogens, and elevated natural killer cell cytotoxicity.[82,85] Women caregivers are more likely to report their health as poor, have poorer physical functioning or more likely to have a chronic or serious illness.[86,87]

Preventative health care also suffers for caregivers. Many caregivers delay or skip their own doctor/dentist appointments.[45,86] Caregivers also reported less time exercising, poor eating habits, weight gain or loss, and sleep deprivation.[45]

B. Psychological Health

Caregivers are more stressed, more depressed, and have lower levels of subjective well-being than non-caregivers.[84,87] Female caregivers are more distressed than men.[88-90] Women who provided 36 or more weekly hours of care to a disabled spouse were almost 6 times more likely than non-caregivers to experience depressive or anxious symptoms.[90] Women spend more time performing "hands-on" caregiving tasks, report higher levels of caregiver burden, role strain and role conflict, less likely to obtain informal support or engage in preventative health behaviors, and report more psychiatric symptoms than men.[89] Financial strain and economic hardship are sources of anxiety in female caregivers.[81,86]

C. Summary

A review of the empirical literature has found that female caregivers are at increased risk for physical and mental health problems. Caregiving demands often are physically, emotionally, socially, or financially challenging. The demands frequently outweigh resources which results in stress.[91] This stress can lead to lifestyle behaviors that put women at risk for cardiovascular diseases such as diabetes or hypertension.[84] Future studies will need to examine physical health outcomes in caregivers.

IV. Caregiving and Cardiovascular Health Outcomes

Cardiovascular disease (CVD) is the leading cause of death in the United States.[2] The American Heart Association has identified seven cardiovascular health metrics including: 1) not smoking, 2) being physically active, 3) having normal blood pressure, 4) blood glucose, 5) total cholesterol levels, 6) weight, and 7) eating a healthy diet. Meeting a greater number of cardiovascular health metrics was associated with a lower risk of CVD mortality in the general population, but overall the prevalence of meeting all seven cardiovascular health metrics was low.[92] Heart disease and stroke continue to be the leading cause of morbidity and mortality in women, with one in three women having some form of cardiovascular disease (CVD).[2] This section will review the literature examining caregiving and risk factors influencing cardiovascular health in women. Table 2.5 presents a summary of relevant studies and their strengths and weaknesses.

A. Caregiving and Cardiovascular Risk Factors in Female Caregivers

Women have been called the “heart keepers” of families.[4] Participants in “The National Study of Women’s Awareness, Preventive Action, and Barriers to Cardiovascular Health” cited caretaking responsibilities as the third most frequent barrier for heart health.[4,93] Awareness that personal level of cardiovascular risk was positively associated with taking steps to lower risk in family and themselves.[4] General life stress and multi-caregiving responsibilities made diabetes self-management difficult in a study of African American women.[94] Caring for a disabled spouse 9 hours or more per week was associated with increased risk of CVD women from the Nurses' Health Study.[95] Caregivers providing in-home care for a spouse with Alzheimer's disease had higher Framingham Risk Scores than controls. Higher blood pressure in the caregivers compared to the controls made the greatest contribution to this difference.[96] Caregivers of cardiac patients reported less physical activity and had a higher waist circumference than controls.[97]

B. Psychosocial Risk Factors

Women in the Framingham study reported significantly more emotional distress than men. Women holding clerical jobs had almost twice the risk of CVD than housewives.[1] Depression is a risk factor for CVD in both healthy individual and individuals with existing CVD.[98,99] In women with CVD, depression and anxiety are associated with increased family stress.[99] After controlling for risk factors of CVD in a group of dementia family caregivers, researchers found that increased depressive symptoms and reaction to recipient problem behaviors were independent significant predictors of development of CVD within 18 months.

C. Veterans and Cardiovascular Health

After adjustment for several potential confounding variables, OEF/OIF veterans with mental health diagnoses had a significantly higher prevalence of all cardiovascular risk factors.[100] Polytrauma team members caring for veterans with TBI reported moderate to high levels of emotional exhaustion putting them at risk for burnout. Two important coping strategies to manage stress were promoting a healthy lifestyle and connecting with others.[101] Cardiovascular risk factors have not been study in veterans with traumatic brain injury or their family caregivers.

D. Summary

Women who were aware of their personal risk for CVD took preventative action.[4] Caregiving and caregiver strain are associated with lifestyle and psychosocial risk factors for CVD including poor diet, decreased physical exercise, depression, and anxiety. Preliminary studies indicate that female caregivers are at risk for CVD, making this an area rich for future research.

V. Conclusion

Traumatic brain injury has been labeled the "signature wound" of the Iraq and Afghanistan conflicts. Although the majority of these cases are classified as mTBI, there are no data available to estimate how many mothers and wives are caring for veterans with mTBI. Veterans with mTBI exhibit a number of neurobehavioral or postconcussive symptoms. This review of the empirical research of caregivers of individuals with TBI revealed that caregiver stress is mediated by cognitive dysfunction and behavioral and personality changes in the care recipient. Female spouses exhibited the most distress. Studies have shown that both civilian and veteran caregivers suffer health deterioration, mental and emotional distress, isolation, and loss of income. The stress of multiple caregiving responsibilities is associated with an increase in CVD risk in women.

The majority of these studies have been conducted in caregivers of severely brain injured individuals. Limitations of these studies include lack of consistency in measurements, sampling biases, and lack of experimental design. In many studies, use of convenience samples limited the generalizability of findings. One strikingly under-developed area of caregiving scholarship is caregiver physical health outcomes, particularly objective physiological outcomes. Few studies report the amount of care provided or the level of impairment in activities of daily living experienced by the care recipient. Future studies will need to provide more descriptive information with regard to the amount and type of care needed by individuals with TBI including mTBI. Studies to date have focused on the psychosocial aspects of caregiver burden, but future research to examine physical health outcomes in caregivers is sorely needed. By identifying caregivers at risk for CVD, researchers can design interventional studies that foster health promotion for both the caregiver and the veteran.

Table 2.1: Government & Private Foundation Reports

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	DISCUSSION & LIMITATIONS
Tanielian, T., Ramchand, R., Fisher, M. Sims, C, Harris, R., & Harrell, M. (2013) Military Caregivers: Cornerstone of Support for Our Nation's Wounded, Ill, and Injured Veterans. Retrieved from http://www.rand.org/content/dam/rand/pubs/research.reports/RR200/RR244/RAND_RR244.pdf. Accessed on November 19, 2013.	Phase 1 funded by Elizabeth Dole Foundation- examine needs of military caregivers		Reviews existing research	Unique population, unique challenges, self-sacrifice What do caregivers do? Health Assistance, case management, mental & emotional support, legal financial & advocacy roles. Effect on caregiver – health deterioration, mental & emotional distress, isolation, loss of income
National Alliance for Caregiving & United Health Foundation. Caregivers of Veterans – Serving on the Homefront. Bethesda, M.D. November 2010. Retrieved from http://www.caregiving.org/data/2010.caregivers_of_veterans_FullReport_web_Final.pdf. Accessed on November 27, 2013.	To assess the needs of caregivers of veterans from WWII to Iraq & Afghanistan.	Survey 462 family caregivers 6 Focus groups in 3 cities	Mixed Method Online survey Focus group	**Key findings –** 96% women; 65% high burden caregiving; 68% high emotional stress; 50% financial hardship 29% of veteran with TBI; only 29% felt had choice to care for veteran; TBI – more likely to help with finances; TBI -78% less time exercising; 76% weight gain or loss; 68% poor eating habits; others do not understand what going through for TBI/PTSD

Table 2.1: Government & Private Foundation Reports				
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**DISCUSSION & LIMITATIONS**
Tanielian, T. & Jaycox, L, Schell, T.L., Marshall, G.N., Burnam, M.A. 2008. *Invisible Wounds of War: Summary and Recommendations for Addressing Psychological and Cognitive Injuries.* Santa Monica, CA: RAND Corporation. Retrieved from http://www.rand.org/content/dam/rand/pubs/monographs/2008/RAND_MG720.1.pdf. Accessed on November 17, 2013.	The purpose of this study was to examine the prevalence, cost, programs & gaps of mental & cognitive conditions in returning	Survey 1965 veterans & service members	Review of Literature Survey	**Key Findings-** little is known about # of TBI and limited research on long term effects TBI can have long term, cascading effects Most TBI recover in 3-12 months Mild TBI – 5-15% suffer protracted problems TBI & depression – more functional impairment; more anxiety, more aggressive behavior & poor social functioning TBI – more likely to experience Alzheimer & Parkinson's; Mild TBI – 2 x more likely alcohol or criminal discharge; Mild TBI – more missed work days; TBI – more verbally aggressive & angry

Table 2.1: Government & Private Foundation Reports				
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**DISCUSSION & LIMITATIONS**
IOM (Institute of Medicine) (2009) *Gulf War and Health Volume 7: Long Term Consequences of Traumatic Brain Injury.* Washington D.C The National Academies Press.	To detail the long term consequences of TBI, the committee reviewed1,900 articles.		Committee Literature Review	**Key Findings for mild TBI:** Sufficient Evidence of an association: • TBI & Depression • TBI & aggressive behaviors • TBI & post concussion symptoms (memory problems, dizziness, & irritability) Limited evidence of an Association • Mild TBI with LOC or amnesia and unprovoked seizures • Mild TBI & ocular & motor deterioration • Mild TBI with LOC and dementia of Alzheimer type • Mild TBI with LOC and Parkinsonism • Mild TBI and PTSD in military populations+* Inadequate/Insufficient evidence • Mild TBI & neurocognitive deficits • Mild TBI (without LOC) and dementia • Mild TBI & PTSD in civilian populations • Mild TBI - long term adverse social fx

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
6. Spelman, J., Hunt, S., Seal, K., Burgo-Black, A. (2012) Post Deployment Care for Retuning Veterans*. Journal of General Internal Medicine.*27(9):1200-1209. DOI: 10.1007/s11606-012.2061-1.	A comprehensive review of health risks of deployment and evidence – based management guidelines.		Narrative review	Blast exposure – TBI, mental health concerns-PTSD, musculoskeletal pain, substance abuse, sleep disturbances, impairments in family & social functioning	2.4 million deployed since 9/11/01 Concussion & PCS increase risk of PTSD, chronic pain, & headaches – overlap of symptoms
7. Elder,G., Mitsis, E., Ahlers, S., & Cristian, A. (2010) *Psychiatric Clinics of North America.*33:757-781. Doi:10.1016/j.psc.2010.08.001*.*	Discuss current controversies related to TBI & PTSD Detailed discussion of pathophysiology		Review article	Mechanism of blast related injury Primary blast wave & the brain Neuroimaging in mild TBI – diffusion tensor imaging	TBI – more organic symptoms – headache, dizziness, visual complaints, & cognitive disturbance PTSD nightmares & hyperarousal TBI education – memory, anger management, relaxation, diet & exercise

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
8. Okie, S. (2005) Traumatic Brain Injury in the War Zone.*NEJM.*.352(20):2043-2047.	Perspective	Interview regarding 2 case studies		According Joint Theatre Trauma Registry – 22% of injured soldiers to Landstuhl had injuries head, neck, face	Describes pathophysiology of blast injury – TBI TBI assessed mild, moderate, severe by LOC & amnesia
9. Owens, B., Kragh, J., Wenke, J., Macaitis, J., Wade, C., Holcomb, J. (2008) Combat Wounds in Operation Iraqi Freedom and Operation Enduring Freedom. *Journal of Trauma.*64(2):295-299. DOI: 10.1097/TA.0b013e318163b875	Describe wound patterns & mechanisms in current conflicts	3102 casualties	Chart review of Joint Theater Trauma Registry 10/2001-1/2005	Explosive mechanism - 78% Head 8%; eyes 6%; face 10% abdomen 11%, extremity -54%	Greater proportion of head & neck wounds

Table 2.2: TBI Patient Characteristics Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
11. Warden., D. (2006) Military TBI During the Iraq and Afghanistan Wars. *Journal of Head Trauma Rehabilitation.*21(5):398-402.	Discuss TBI in the military and data from Walter Reed	433 veterans with TBI Walter Reed	Descriptive	19% TBI concomitant amputation – lower more common Mild TBI less 50% Moderate & Severe 56% Closed TBI 88%	PTSD – re-experiencing & flashbacks PPCS – headache, nausea/vomiting, dizziness
12. Lew, H., Poole, J., Alvarez, S., Moore, W. (2005) Soldiers with Occult Traumatic Brain Injury. *American Journal of Physical Medicine & Rehabilitation.* 84:393-398.	Describe the role of neuropsychological & electrophysiological measures in TBI	2 case studies	Commentary	Problems follow through Personality change –↑ irritability & argumentation Problem when greater speed & executive fx needed; poor problem solving	Protective armor improves survivability Kevlar armor reduces penetrating injuries Head remains susceptible to concussive forces Dramatic change in function 3-5 months post injury

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
13. Martin, E., Lu, W., Helmick, K., French, L., Warden, D. (2008) Traumatic Brain Injuries Sustained in the Afghanistan and Iraq Wars. *AJN.* 108(4): 40-47.	To describe the experience of the Defense and Veterans Brain Injury Center at Walter Reed and present a case to illustrate nurse's role in assessment and care of TBI patient.		Review article with composite case study.	Authors describe pathophysiology of Blast-related TBI, screening and assessment, and treatment. "Post TBI symptoms can interfere with personal relationships, as well as with the patient's daily routine."	
14. IOM (Institute of Medicine) 2010.*Returning Home from Iraq and Afghanistan: Preliminary assessment of readjustment needs of veterans, service members and their families.* Washington D.C. The National Academies Press.	Assess needs of returning veterans and service members.		Committee – review of Literature & interview of stakeholder	**Key findings –** TBI can go undetected until service member comes home and can't function; some dysfunction lessens overtime- psychiatric sequelae apparent years after injury. VA-to develop protocols for long term management of TBI	

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
15. Lew, H., Poole, J., Vanderploeg, R., Goodrich, G., Dekelboum,S., Guillory, S., Sigford, B. and Cifu, D. (2007) Program Development and defining characteristics of returning military in a VA Polytrauma Network Site. *Journal of Rehabilitation Research and Development.*44:1027-1034	Reports the initial implementation of PNS clinic & describe clinical characteristics of first 62 patients.	62 patients seen in PA clinic from 7/2006-2/2007	Cross-sectional descriptive Tools: H & P Neurobehavioral symptom inventory Hearing & Vision screening	82% OEF/OIF vets 79% explosive device 50% LOC 31% alteration of consciousness 97% three or more PCSS- sleep, hyperarousal, mood symptoms, Headache & cognitive complaints 71% PTSD 55% cognitive disorders 58% tinnitus 75% visual problem	3 Screening questions 42% co-occurrence of PTSD & cognitive disorder People with mild TBI – PTSD increase risk for PPCS

Table 2.2: TBI Patient Characteristics Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
16. Evans, C, Andre, J., Pape, T., Steiner, M., Stroupe, K., Hogan, T., Weaver, F., Smith, B. (2013) An Evaluation of the Veterans Affairs Traumatic Brain Injury Screening Process among Operation Enduring Freedom and/or Operation Iraqi Freedom Veterans.*PM & R*.5(3):210-220 DOI:.org10.1016/j.pmrj.2012.12.004	Describe results of TBI screening program & characteristics of veteran & facility that completed the screen.	170,681 OEF/OIF from 4/2007-9/2008	Retrospective cohort study	91.6% received screen 25% TBI exposure-85%blast 20.5% positive screen	Male gender, army, multiple deployments & mental health diagnosis associated with positive screen
17. Bigler, E. (2013) Neuroimaging Biomarkers in Mild Traumatic Brain Injury (mTBI). *Neuropsychology Review.*23:169-209. DOI:10.1007/s11065-013-9237-2	Review contemporary imaging methods to detect abnormalities associated with mTBI		Review	MRI detect hemosiderin deposits a& white matter abnormalities-diffusion tensor imaging	Extensive research needed to identify blood biomarkers Majority of mTBI recover fully
18. Morey, R., Haswell, C., Selgrade, E., Massoglia, D., Liu, C., Weiner, J., & McCarth, G. (2013) Effects of Chronic Mild Traumatic Brain Injury on White Matter Integrity in Iraq and Afghanistan War Veterans. *Human Brain Mapping.*34:2986-2999 DOI: 10.1002/hbm.22117	Examine mTBI & associated variables LOC, feeling dazed or confused, #TBI) would influence white matter integrity	Mild TBI =30with comorbid PTSD, Depression Control=42 Duke/VA	Diffusion imaging	Loss of white matter integrity associated with LOC but diagnosis of depression or PTSD	Blast related TBI-involves cascade of inflammatory & neurochemical events

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
19. Jeter,C., Hergenroeder, G., Hylin, M., Redell,J., Moore, A., Dash, P. (2013) Biomarkers for the diagnosis and prognosis of Mild Traumatic Brain Injury/Concussion. *Journal of Neurotrauma.* 30:657-670. DOI:10.1089/neu.2012.2439	Review of status of biomarkers in diagnosing of TBI		Review paper	Biomarkers with promise: S110B, Glial fibrillary acidic protein (GFAP), NAA, myelin basic protein (MBP)	ApoE4 –affect memory function after TBI Much more research needed to identify biomarkers & epigenetics and symptomology

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
20. Tanielian, T. & Jaycox, L. Schell, T.L., Marshall, G.N., Burnam, M.A. 2008. *Invisible Wounds of War: Summary and Recommendations for Addressing Psychological and Cognitive Injuries.* Santa Monica, CA. RAND Corporation. Retrieved from [http://www.rand.org/content/dam/rand/pubs/monographs/2008/RAND_MG720.1.pdf.](http://www.rand.org/content/dam/rand/pubs/monographs/2008/RAND_MG720.1.pdf) Accessed on November 17, 2013.	The purpose of this study was to examine the prevalence, cost, programs & gaps of mental & cognitive conditions in returning	Survey 1965 veterans & service members	Review of Literature Survey	**Key Findings-** little is known about # of TBI and limited research on long term effects TBI can have long term, cascading effects Most TBI recover in 3-12 months Mild TBI – 5-15% suffer protracted problems TBI & depression – more functional impairment; more anxiety, more aggressive behavior & poor social functioning TBI – more likely to experience Alzheimer & Parkinson's; Mild TBI – 2 x more likely alcohol or criminal discharge; Mild TBI – more missed work days; TBI – more verbally aggressive & angry	
21. Lew, H., Poole, J., Guillory, S., Salerno, R., Leskin, G., Sigford, B. (2006) Persistent problems after traumatic brain injury: The need for long term follow-up and coordinated care. *Journal of Rehabilitation Research & Development.*43(2): vii-x.	To determine the prevalence of a constellation of problems following discharge from PA VA facility	138 DVBIC program from 1993-2003	Chart Review	Those that missed f/u had more emotional problems at baseline but fewer cognitive impairment	F/u patients – persistence of cognitive & emotional issues 2 years post Combat TBI significant ↑vision, light sensitivity, sleep & PTSD problems than non-combat TBI

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
22. Hoge, C., McGurk,.D., Thomas,J., Cox, T., Engel, C. & Castro, C. (2008) Mild Traumatic Brain Injury in U.S. Soldiers Returning from Iraq. *NEJM.* 358(5); 453-463.	To assess prevalence & significance of self-reported mild TBI	2525 army soldiers 3-4 month after return – Walter Reed	Epidemiologic study	4.9% injuries with LOC 10.3% injuries with altered mental status LOC – 44% PTSD versus 27% of those with altered mental status	Mild TBI with LOC – report more poor health, missed work days, medical visits, & PPCS Adjust for PTSD & depression – headache only outcome PTSD & depression- important mediator mild TBI & physical health problems
23. Carlson, K., Nelson, D., Orazem, R., Nugent, S., Cifu, D., Sayer, N. (2010) Psychiatric Diagnoses Among Iraq and Afghanistan War Veterans Screened for Deployment-Related Traumatic Brain Injury. *Journal of Traumatic Stress.*23(1):17-24. DOI: 10.1002/jts.20483	To examine rates of psychiatric disorders in relation to TBI screen & confirmed cases	13,201 veterans Midwest	Data base screen	Positive screen: 2279 Confirmed TBI: 836 50% one psychiatric dx 25% PTSD 25% depression	**Lists ICD9 codes** + screen but no TBI – 3x more likely PTSD, 2x more depression & substance abuse than negative screen confirmed TBI – PTSD & other anxiety disorders

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
24. Wilk, J., Herrell, R., Wynn, G., Riviere, L., Hoge, C. (2012) Mild Traumatic Brain Injury (Concussion), Post Traumatic Stress Disorder, and Depression in US Soldiers Involved in Combat Deployments: Association with Post deployment Symptoms *Psychosomatic Medicine.* 74:249-257. DOI:10.1097/PSY.0b013e318244c604	To examine the associations of single & multiple deployments mTBI on post deployment health	1502 Army soldiers 4-6 months returning from deployment	Surveys	17% mTBI 59% > 1TBI LOC was headache PTSD & depression most explain PCS	Current screens do not distinguish mTBI from other caused PTSD & depression Need randomized trials of collaborative care for PCS
25. Maguen, S., Lau, K., Madden, E. Seal, K. (20120 Relationship of screen-based symptoms for mild traumatic brain injury and mental health problems in Iraq and Afghanistan veterans: distinct or overlapping symptoms? *Journal of Rehabilitation and Research Development.*49:1115-1126 DOI:.org/10.1682/JRDD.2011.02.0015	Identify symptoms that distinguish TBI, PTSD, & depression	1713 OIF/OEF veterans screened 4/2007-1/2010	Factor analytic techniques Chart review: TBI Screen PTSD screen Depression screen (PHQ-2)	TBI – 2 x depression & PTSD Irritability shared TBI & PTSD Emotional numbing – PTSD & depression Unique TBI- dizziness, headaches, & memory problems	Hypervigilance & sleep problems – 4th factor First line treatment – focus on insomnia, emotional regulation, & cognitive dysfx

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
26. Seal, K., Metzler, T., Gima, K., Bertenthal, D., Maguen, S., & Marmar, C. (2009) Trends and Risk Factors for Mental Health Diagnoses Among Iraq and Afghanistan Veterans using Department of Veterans Affairs Health Care, 2002-2008. *American Journal of Public Health.* 99(9):1651-1658. DOI:10.2105/AJPH.2008.150284.	To investigate longitudinal trends and risk factors for mental health diagnosis among Iraq & Afghanistan veterans.	289328 Iraq & Afghanistan veterans from 2002-2008	Review of VA national database	36.9% -mental health diagnosis 21.8% PTSD 17.4% depression	41% of veterans enroll in VA services Women more likely depressed; men more likely substance abuse
27. Vanderploeg, R., Curtiss,G., Luis,C. Salazar, A. (2007) Long-term morbidities following self-reported mild traumatic brain injury. *Journal of Clinical and Experimental Neuropsychology.*29(6):585-598.	To examine long term psychiatric, neuropsychological morbidities of mTBI.	3214 control 539 accident 254mTBI w/ altered LOC	Cross-sectional, cohort	mTBI - ↑depression & PCS, vision & gait problems	mTBI – poor psycho-social outcomes, underemployment, low income & marital problems years after injury
28. Schneiderman, A., Braver, E., Kang, H. (2008) Understanding sequelae of injury of mechanisms and mild traumatic brain injury during conflicts in Iraq and Afghanistan: Persistent Postconcussive symptoms and post traumatic stress disorder. *American Journal of Epidemiology.*167(12):1446-1452. DOI:10.1093/aje/kwn068	To estimate mTBI occurrence in relation to combat theatre injuries, prevalence of PTSD, & PCS	7,259 veterans in DC area 2,235 surveys returned	Cross-sectional	12% mTBI 11% PTSD Strongest factor for PPCS-PTSD	35%mTBI – 3 or more PPCS symptoms

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
29. Hartlage, L., Durant-Wilson, D., Patch, P. (2001) Persistent neurobehavioral problems following mild traumatic brain injury. *Archives if Clinical Neuropsychology.* 16:561-570.	To assess behavioral changes from pre-injury baseline with persistent post injury neurobehavioral problems.	70 patients referred for neuropsych exam following MTBI 40 normal **Civilian**	Longitudinal – 6 months & 12 months Data collected from patient & family Behavioral changes included absentmindedness, fearfulness, agitation & increased anger	21% significant behavioral impairment at 12 months post injury Neuronal degeneration may account for change	85% recover 15% persistent symptoms Debate if neurogenic versus psychogenic
30. McCrea, M., Iverson, G., McAllister, T., Hammeke, T., Powell, M., Barr, W., Kelly, J. (2009) An Integrated Review of Recovery after Mild Traumatic Brain Injury (MTBI): Implications for Clinical Management. *The Clinical Neuropsychologist.*23:1368-1390. DOI:10.1080/13854040903074652.	To summarize the evidence base that advances our understanding of the natural history of MTBI.		Literature Review	MTBI – neuropsych recovery by 3 months Complicated MTBI – structural damage on neuroimaging Rest after MTBI until symptoms disappear to avoid further damage There is a window of neurobiological vulnerability PTSD, depression, anxiety, chronic pain complicate recovery from MTBI MTBI research – 50 years but major advances in last 10 year due to fMRI	

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
31. Brenner, L., Ivins, B., Schwab, K., Warden, D., Nelson, L., Jaffee, M., Terrio, H. (2010) Traumatic Brain Injury, Posttraumatic Stress Disorder, and Postconcussive Symptom Reporting Among Troops Returning from Iraq. *Journal of Head Trauma Rehabilitation.* 25(5):307-12.	Analyze the contribution of mTBI & PTSD to PC symptoms during post deployment Health Assessment.	1247 soldiers Fort Carson Brigade	Cross sectional study design WARCAT –TBI- includes neuropsych symptoms Clinician interview PTSD screen – reexperiencing, numbing, avoidance, hyperarousal)	PTSD & mTBI – more strongly associated with PC symptoms – 6.27 adjusted prevalence than either alone	Data collected immediately post deployment
32. Wall, P. (2012) Posttraumatic Stress Disorder and Traumatic Brain Injury in Current Military Populations: A Critical Analysis. *Journal of the American Psychiatric Nurses Association.* 18(5):278-298. DOI:10.1177/1078390312460578.	The purpose of this article is to perform a critical analysis of the literature to identify current rates of PTSD and TBI and effects on PPCS.	20 studies met inclusion criteria	Lit search: key words posttraumatic stress disorder, PTSD, traumatic brain, TBI, postconcussive syndrome, veteran, Military	Comorbid PTSD & TBI – greater Postconcussive symptoms than either condition alone Case series or surveys, retrospective record review, cohort studies	Limitation – lack of consistency of measures, sampling biases, lack of experimental design Future longitudinal studies needed.

Table 2.2: TBI Patient Characteristics Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
33. Peskind, E., Petrie, E., Cross, D., Pagulayan, K., McCraw, K., Hoff ,D., Hart, K., Yu, C., Raskind, M., Cook, Minoshima, S. (2011) Cerebrocerebellar hypometabolism associated with repetitive blast exposure mild traumatic brain injury in 12 Iraq war veterans with persistent post-concussive symptoms. *Neuroimage.*54:s76-s82. DOI:10.1016/j.neuroimage.2010.04.008.	To objectively examine structural or functional brain damage in Iraq war veterans versus control using FDG=-PET imaging.	12 veterans 12 cognitively normal adults	Comparative design Fluorodeoxyglucose positron emission tomography NSI PCL-M Neuropsych battery	Veterans with mTBI with and without PTSD demonstrated decreased cerebral metabolic rate of glucose in cerebellum, pons, & medial temporal lobes	Regional brain hypometabolism may constitute a neurobiological substrate for chronic PCS Subtle impairment in verbal fluency, cognitive processing speed, attention & working memory in veterans
34. Polusny, M., Kehle, S., Nelson, N., Erbes, C., Arbisi, P., Thuras, P. (2011) Longitudinal Effects of Mild Traumatic Brain Injury and Posttraumatic Stress Disorder Comorbidity on Post deployment Outcomes in National Guard Soldiers Deployed to Iraq. *Archives General Psychiatry.* 68(1):79-89.	To assess longitudinal associations between mTBI & PTSD reported in theatre & long term psychosocial outcomes in national guard soldiers.	950 US National Guard	Longitudinal cohort Tools: VA TBI Screening-3 question PCL-M PHQ-15 Beck Depression Inventory Alcohol use Social Adjustment scale WHO QOL	Self-reported concussion 9.2% in theatre – 22.0% at 1 year After adjusting for PTSD – mTBI not associated with postconcussive symptoms	PHQ-15 (stomach pain, back pain, pain in arms, headaches, chest pain, dizziness, fainting spells, feeling heart race, SOB, constipation, feeling tired, sleep disturbance

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
35. Lew, H., Otis, J., Tun, C. Kerns, R., Clark, M., Cifu, D. (2009) Prevalence of chronic pain, posttraumatic stress disorder, and persistent postconcussive symptoms in OIF/OEF veterans: Polytrauma clinical triad. *Journal of Rehabilitation Research & Development.* 46:697-702	Examines the prevalence of OIF/OEF veterans report chronic pain, PTSD, & PPCS symptoms	340 veterans PAVA 1/2007-10/2008	Chart review	81% pain; 68% PTSD, 66.8% PPCS 42.1% all three	Back & head most chronic pain locations More translational research needed to understand the interrelationship among 3 conditions & EBT
36. Romesser, J., Booth, J., Benge, J., Pastorek, N., Helmer, D. (2012) Mild traumatic brain injury and pain in Operation Iraqi Freedom/Operation Enduring Freedom veterans. *Journal of Rehabilitation Research & Development.*49 (&):1127-1136. DOI:.org/10.1682/JRRD.2010.12.0238	Describe pain experience in OEF/OIF veterans with/without TBI.	529 veterans	Retrospective chart review	Headache, low back & neck pain 21% TBI – pain 31.9% pain mTBI with disorientation 36.9% LOC mTBI	PTS strongly related to pain experience mTBI with LOC- predicted headache May have long term headache pain
37. Theeler, B., Erickson, J. (2009) Mild Head Trauma and Chronic Headache in Returning US Soldiers. *Headache.*49:529-534. DOI:10.1111/j.1526-4610.2009.01345.x.	To determine incidence and type of headache characteristic among US Army soldiers deployed to Iraq.	81 soldiers - 1 year post deployment	Retrospective Cohort Study	41% had head/neck trauma concussion w/ AOC- 22% concussion with LOC-19% Migraine – 78%	Limited small sample size, retrospective design, clinic-based population

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
38. Ruff, R., Ruff, S., Wang, X. (2008) Headaches among Operation Iraqi Freedom/Operation Enduring Freedom veterans with mild traumatic brain injury with exposures to explosions. *Journal of Rehabilitation Research & Development.*45(7):941-952. DOI:10.1682/JRRD.2008.02.0028.	Examine the hypothesis that veterans w/ mTBI caused by explosion & residual cognitive deficits- ↑headache.	126 veterans 80 mTBI Midwest	Cross sectional Tools: TBI Screen Neurological exam Neuropsychological assessment	Veterans with persistent neurocognitive deficits more likely have headaches, PTSD, impaired sleep, migraine	52% of veterans with mTBI had impaired olfaction.
39. Iverson, G., Gaetz, M., Lovell, M. and Collins, M. (2004) Cumulative effects of concussion in amateur athletes. *Brain Injury.* 18(5):433-443.DOI:10.1080/02699050310001617352.	To examine the possibility that athletes with multiple concussions show cumulative effects.	38 athletes both high school and college 19 concussion & 19 control	Comparative design (ImPACT)	Athletes with multiple concussion 7.7 times major drop in memory performance	
40. Guskiewicz, K., McCrea, M., Marshall, S., Cantu, R., Randolph, C., Barr, W., Onate, J., and Kelly, J. (2003) Cumulative Effects Associated With Recurrent Concussion in Collegiate Football Players: The NCAA Concussion Study. *JAMA.*290(19):2549-2555.	To estimate the incidence of concussion and time to recovery after concussion in collegiate football players.	2905 collegiate football players 1999-2001	Prospective cohort study Graded Symptom Checklist	Slowed recovery associated with a history of multiple previous concussions	↑risk of future injury due to neuronal vulnerability- neurometabolic cascade - ↑lactate production- lead neurons more vulnerable to secondary ischemic injury

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
41. Carlson, K., Meis, L., Jensen, A., Simon, A., Gravely, A., Taylor, B., Bangerter, A., Schaaf, K., Griffin, J. (2012) Caregiver Reports of Subsequent Injuries Among Veterans with Traumatic Brain Injury after Discharge from Inpatient Polytrauma Rehabilitation Programs. *Journal of Head Trauma Rehabilitation.* 27(1):14-25. DOI:10.1097/HTR.0b013e318236bd86	Examine prevalence & risk factors for nonfatal injuries among TBI post discharge	1045 564 completed survey	Survey TBI 2001-2009 FACES STUDY	32% post discharge injuries Falls-49% 37% MVA	Caregiver poor health-veteran subsequent injury Vision loss, hearing loss, speech problems, chronic pain, & depression – more likely injury
42. Vanderploeg, R., Belanger, H., Curtiss, G. (2009) Mild Traumatic Brain Injury and Posttraumatic Stress Disorder and Their Associations with Health Symptoms. *Arch Phys Med Rehabilitation.* 90:1084-93. DOI:10.1016/j.apmr.01.023	To determine the association of symptoms & psychiatric diagnoses with remote mTBI & current diagnosis of PTSD.	3 groups of Viet Nam army vets Healthy control- 3218 MVA without Head injury - 548 MVA with mTBI -278	Cross sectional cohort History questionnaire (Used questions from Hoge study)	mTBI associated with headaches, sleep problems, memory problems & fainting after controlling for PTSD	mTBI can prolong recovery from preexist conditions such as PTSD Need post deployment interventions – stress management, sleep hygiene, education substance abuse, & alternative coping strategies

Table 2.2: TBI Patient Characteristics Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
43. Rauh, M., Aralis, H., Melcer,T., Macera,C., Sessoms, P., Bartlett,J. & Galarneau, M. (2013) Effects of traumatic brain injury among U.S. service members with amputation. *JRRD.*50(2):161-172. Doi.org/10.1682/JRRD.2011.11.0212	Determine frequency of TBI among service members with amputation	546 from EMED (Trauma Registry) &CHAMPS	Chart review	23.3% had TBI diagnosis	Amputation with TBI - more likely infection, cellulitis, or DVT or PE
44. IOM (Institute of Medicine) (2014) *Gulf War and Health, Volume 9: Long-Term Effects of Blast Exposures.* Washington D.C. The National Academies Press.	To detail the long-term health effects of exposure to blast.		Committee Literature Review	**Key findings related to TBI:** *Sufficient evidence for an association:* PCS & persistent headaches in cases of mTBI *Limited evidence of an association:* Chronic traumatic encephalopathy & progressive cognitive & behavioral decline in cases of recurrent blast TBI *Additional Conclusion:* Sufficient evidence - substantial overlap in symptoms of mTBI & PTSD	

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
45. National Alliance for Caregiving & United Health Foundation. Caregivers of Veterans – Serving on the Homefront. Bethesda, M.D. November 2010. Retrieved from http://www.caregiving.org/data/2010.caregivers_of_veterans_FullReport_web_Final.pdf. Accessed on November 27,2013.	To assess the needs of caregivers of veterans from WWII to Iraq & Afghanistan.	Survey 462 family caregivers 6 Focus groups in 3 cities	Mixed Method Online survey Focus group	**Key findings –** 96% women; 65% high burden caregiving; 68% high emotional stress; 50% financial hardship 29% of veteran with TBI; only 29% felt had choice to care for veteran; TBI – more likely to help with finances; TBI - 78% less time exercising; 76% weight gain or loss; 68% poor eating habits; others do not understand what going through for TBI/PTSD	
46. Verhaeghe, S., Defloor, T., Grypdonck, M. (2005) Stress and coping among families of patients with traumatic brain injury: a review of the literature. *Journal of Clinical Nursing,* 14, 1004-1012.	This review of the literature examined psychological reactions of families with TBI utilizing stress-coping literature & systems theory	N= 94 English articles	Literature review	Stress level high - need professional intervention 10-15 years later Young families with little support are most vulnerable Better families cope-better patient recovery Women higher stress & depression Faith basis of effective coping	Most vulnerable include partners, children, families with financial or medical problems Conflict with professional carers should be avoided Future research – family interventions

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
47. Kreutzer, J., Gervasio, A., Camplair, P. (1994) Primary caregivers' psychological status and family functioning after brain injury. *Brain Injury.* 8(3):197-210.	This study investigated the prevalence of psychological distress and unhealthy family functioning in caregivers of TBI patients.	62 adult outpatients Medical college of Virginia	Cross-sectional Tools: BSI FAD Statistics: Descriptive	50% distress by BSI General Distress Index 33% ↑ anxiety 25% depression 74% impaired family communication	Spouses ↑ depression compared to parents Trend – spouses ↑ unhealthy family fx
48. Linn, R., Allen, K., Willer, B. (1994) Affective symptoms in the chronic stage of traumatic brain injury. *Brain Injury.*8(2): 135-147.	To examine disability and psychological distress in TBI subjects & spouse.	60 TBI subjects & spouse during weekend retreat Buffalo, NY	Cross-sectional Tools: Cognitive Disability & Social Aggression Health & Activity Limitations Survey SCL-90 Statistics: stepwise multiple regression	TBI – 70% depression & 50% anxiety Spouse- 73% depression; 55% anxiety TBI -↑ rating of cognitive disability & social aggression - ↑ anxiety & depression	Average TBI 6 years post injury Gender more impt in spouse – females ↑anxiety & depression Sample taken from TBI support group

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
49. Marsh, N., Kersel, D., Havill, J. and Sleigh, J. (1998) Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury,* 12(3), 225-238.	Purpose to describe caregiver burden and psychosocial impairment at 6 months post injury.	Hamilton, New Zealand N= 69 caregivers Female- 86% Male -14% Parent -62% Spouse - 29%	Cross-sectional Self-report questionnaires Tools: BDI Head Injury Behavior Rating Scale Caregiver Questionnaire Statistics: multiple regression	TBI patient social isolation – greatest distress for caregiver 39% clinically significant anxiety 38% impaired levels of social adjustment	Difficulties in emotional control of TBI patient – aggression, sudden/rapid mood changes, & argumentativeness – greatest distress for caregiver Limitation: generalizability
50. Livingston, M., Brooks, D. Bond, M. (1985) Patient outcome in the year following severe head injury and relatives' psychiatric and social functioning. *Journal of Neurology, Neurosurgery, and Psychiatry.* 48:876-881.	To examine relatives psychiatric & social functioning for first year following injury.	57 severe TBI 1 year post injury UK	Questionnaires Tools: General Health Questionnaire Global Social Adjustment Leeds scale – anxiety & depression	30% relatives- significant clinical anxiety 3-6 months – 40% psychiatric illness-stress Social maladjustment ↑ at 6 & 12 months	High burden caring for relative through year Predictor of relative psych & social status – symptomatic complaints of injured

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
51. Kruetzer, J., Rapport, L., Marwitz, J., Harrison-Felix, C., Hart, T., Glenn, M., Hammond, F. (2009) Caregivers' Well-Being After Traumatic Brain Injury: A Multicenter Prospective Investigation. *Archives Physical Medicine Rehabilitation.* 90:939-946. DOI:10.1016/j.apmr.200901.010	To describe frequency and magnitude of caregiver's emotional distress and life satisfaction	273 caregivers of patient 1, 2, 5 years injury Mod/Severe TBI who had inpatient rehab	Prospective Cohort Study-Telephone interview Tools: BSI-18 Satisfaction with Life FIM Disability Rating Scale Supervision Rating Scale	34% of sample emotional difficulties- 20% depression Higher caregiver distress patient worse function, needed more supervision, less satisfied with life	Depression, anxiety, somatic symptoms common with caregivers
52. Brooks, N., Campsie, L., Symington, S., Beattie, A., McKinlay, W. (1986) The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry.* 49:764-770.	Identify patterns of change - behavioral disturbance in patient & distress in family - first 5 years post injury & predictors of distress in cg.	Close relative of 42 severely head injured patients UK study	Interview 5 years post injury	Minor problems vision remained Relatives under great strain- Best predictor of strain- magnitude of behavioral & personality change patient	Two behavioral problems ↑- personality change & threats of violence Number of relatives reported feeling afraid of patient

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
53. Koskinen, S. (1998) Quality of life 10 years after a very severe traumatic brain injury (TBI): the perspective of the injured and the closest relative. *Brain Injury.* 12(8):631-648.	The aim of this study was to evaluate factors related to quality of life of injured and strain felt by relatives.	15 Severely injured-10 years post injury Finland	Interview Tools: Questionnaire -Strain Barthel Index-independence Neurobehavioral Rating Scale Rehab Institute of Chicago – Functional Assessment	Functional problems-mobility, balance slowness, tendency to get depressed 85% emotional reaction or personality change	Strain – highest first year & ↓ by 5 years Still moderate strain for many at 10 years Neuro & emotional disturbances correlates of life satisfaction in both patient & relatives
54. Oddy, M., Humphrey, M., Uttley, D. (1978) Stresses upon the Relatives of Head-Injured Patients. *British Journal of Psychiatry.*133:507-513.	To examine the nature & cause of stress on relatives at various stage of recovery.	54 severe injured TBI England 6 & 12 months post injury	Prospective study Tools: Wakefield Depression Interview	25% under significant stress Stress does not diminish with time	Stress-poorly controlled behavior, fear of epilepsy, & physical stress Stress does not diminish with time

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
55. Kreutzer, J., Gervasio, A., Camplair, P. (1994) Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury.* 8(3):211-230.	Examine the relationship of patient variables to caregiver distress.	62 adult Medical college of Virginia Over 50% mild/mod injury	Cross-sectional: BSI FAD Neurobehavioral Problem Checklist Neuropsychological tests	Perception of pt behavior problem- strongest relation to distress Cg somatic c/o related to pt physical problem Cg depression related to > impairment ↑neuropsych- ↓family function	Injury severity little relationship to cg distress Neurobehavioral checklist- predictor of BSI subscale Parents ↓ depression than spouse Cg reported high level anxiety, depression, isolation, mental weariness

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
56. Davis, l., Sander, A., Struchen, M., Sherer, M., Nakase-Richardson, R., Malec, J. (2009) Medical and Psychosocial Predictors of Caregiver Distress and Perceived Burden Following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation,* 24(3), 145-154.	To examine if caregivers' medical & psychiatric histories, coping style, & social support were predictors of global distress & perceived burden	N=114 caregivers recruited from TBI Model System Centers in US	Cross-sectional interview within 2 weeks hospital admission & questionnaires at 1 year annual visit including: Modified Caregiver Appraisal Scale Ways of Coping Questionnaire Multidimensional Scale of Perceived Social Support Disability Rating Scale Statistics: Linear regression models	Caregivers' medical &psychiatric history predicted global support. Increase use of escape-avoidance coping strategy related to increase distress Perceived burden predicted by disability, use of escape-avoidance (emotion focus) & perceived social support	Cognitive-behavioral strategies helpful to caregivers; general stress management techniques Limitation: self-report of history instead of medical record Small number of minorities Structural equation model may have been more useful than linear regression

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
57. Ergh, T., Rapport, L., Coleman, R. and Hanks, R. (2002) Predictors of Caregiver and Family Functioning Following Traumatic Brain Injury: Social Support Moderates Caregiver Distress. *Journal of Head Trauma Rehabilitation.* 17(2): 155-174.	To examine predictors of family dysfunction & caregiver distress in traumatic brain injury.	60 pairs of TBI dyads Midwest Moderate/ Severe brain injury	Cross-sectional design – hierarchical multiple regression Tools: Glasgow coma CAGE Neuropsych measures Patient Competency rating scale Neuropsychology Behavior & Affect Profile (NBAP) Social Provision Scale BSI FAD	Neuro-behavioral disturbance strongest predictor of caregiver distress Social support powerful moderator of distress Family dysfunction by 60-68% of caregivers	Older caregivers less distress than younger Non- support – distress ↑longer time after injury, cognitive dysfunction, & unaware of deficits in care recipient
58. Groom, K., Shaw, T., O'Connor, M. Howard, N. & Pickens, A. (1998) Neurobehavioral Symptoms and Family Functioning in Traumatically Brain-Injured Adults. *Archives of Clinical Neuropsychology.* 13(8):695-711.	To describe the nature of the relationship between neurobehavioral symptoms in TBI patient & family functioning.	153 families Midwest 20% mild 80% moderate or severe	Cross sectional Tools; NBAP FAD PSS (Perceived stress)	Family dysfunction related to neurobehavioral symptoms Depression, pragnosia & indifference related to caregiver stress	Injury severity little impact on family functioning Pragnosia – patient misses the point of discussion Indifference – denial of illness Inappropriate – bizarre behavior

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
59. Cavallo, M., Kay, T., Ezrachi, O. (1992) Problems and changes after traumatic brain injury: Differing perceptions within and between families. *Brain Injury.* 6(4): 327-335.	To characterize subgroups of families based on perceptions of problems and changes after TBI.	34 TBI & friend or relative	Interview Tool: Problem Checklist of NYU Head Injury Family interview	High disagree PHI- ↑ return to work High agreement group- so's higher burden Pt- more c/o of problems executive function	Not all families affected by TBI in the same way SO- endorse temper outbursts, impatience, complaining, & anxiety & tension Pt- problem balance, doing things slowly; forgetful, find words
60. Boycott, n., Yeoman, P., Vesey, P. (2013) Factors Associated with Strain in Careers of People with Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation.*28(2):106-115. DOI:10.1097/HTR.0b013e31823fe07e	To explore factors associated with strain	48 caregvr 9.3 years after injury England	Cross sectional cohort Tools: Caregiver Strain Index Neurobehavioral Fx Inventory Glasgow Outcome	Elevated strain - 42% of caregivers Strain assoc with greater difficulty if patient depressed, memory problems, communication, aggression & motor scale	No one item predictive of strain More neurobehavioral- more strain Injury severity –not significant

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
61. Bayen, E., Pradat-Diehl, P., Jourdan, C., Ghout, I., Bosserelle, V., Azerad, S., Weiss, J., Joel, M., Aegerter, P., Azouwi, P. (2012) Predictors of Informal Care Burden 1 year after a Severe Traumatic Brain Injury: Results from the PariS-TBI study. *Journal of Head Trauma Rehabilitation.*	To investigate predictors of burden 1 year after TBI.	66 patient – caregiver France	Cohort Study Tools: Glasgow Outcome Dysexecutive Q. Medical Outcome-Short 36 Zarit Burden	56% significant burden 44% risk of depression Female (spouse/parent) suffer ↓ in health status-hidden patients	Global handicap & impairment of executive fx – predictors of burden at 1 year Injury severity – not a predictor
62. Rivera, P., Elliott, T. Berry, J., Grant, J. and Oswald, K. (2007) Predictors of caregiver depression among community-residing families living with traumatic brain injury. *NeuroRehabiliation,* 22, 3-8.	Problem: ineffective problem-solving abilities would be predictive of risk for depression in TBI caregivers	N=60 caregivers 57 women; 3 men recruited from the Southeast US (AL,GA, TN, MS,FL)	Cross-sectional, correlational design Tools; Social Problem Solving Inventory Caregiver Burden Scale Pennebaker Inventory of Limbic Languidness (caregiver health) CES-D Statistics; logistic regression	Caregivers at risk depression – higher on physical symptoms & negative orientation to problem solving	Effective intervention may be problem solving training Limitation: cross-sectional design Data on premorbid depression not collected Small sample size limits generalizability

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
63. Rosenbaum, M., Najenson, T. (1976) Changes in Life Patterns and symptoms of Low Mood as Reported by Wives of Severely Brain Injured Soldiers. *Journal of Consulting & Clinical Psychology.* 44(6):881-888.	To determine the effects of brain injury on wives of TBI compared to SCI/control at 1 year	30 Israeli women 10- TBI 6 paraplegics 14- no injuries	Cohort study – Yom Kippur Questionnaire	TBI wives- drastic change in life Veteran – more self-oriented & childlike Wives –isolated TBI wives – assume man's role in family	Change in role from equal partner to role of mother surrogate or nurse
64. Hanks, R., Rapport, L., and Vangel, S. (2007) Caregiving appraisal after traumatic brain injury: the effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation,* 22, 43-52.	Examine factors of caregiving including perceived burden, caregiving relationship satisfaction, beliefs about caregiving & mastery Validate Caregiving appraisal scale	N=60 caregivers in Southeastern Michigan TBI System 77% women 23% men 43% parents 21% spouse 70%African-American	Cross-sectional Questionnaires completed at appointment Tools: Caregiver Appraisal Scale Coping Inventory for Stressful situations FAD FIM Disability Rating Scale Statistics: multiple regression	Half caregivers of moderate TBI dissatisfied caregiving. Satisfaction greater in task-oriented coping. Emotionally-focused coping and perceived social support related to perceived burden.	Limitation – self report may indicate traditional beliefs about caregiving Ideology – related to avoidance-oriented coping-ignore challenges Limited generalizability

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
65. Kreutzer, J., Serio, C., Bergquist, S. (1994) Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation. 9(3):104-115.*	To examine the perceived importance of and the extent to which family needs are met in acute & post-acute periods.	119 family members Virginia	Cross-sectional Tool: Family Needs Q	Information & reassurance judged important Families felt misunderstood, isolated, & unsupported	Pt had mild, mod, & severe injury Longer post injury – more needs unmet Females & lower income- ↑needs unmet
66. Chronister, J., Chan, F., Sasson-Gelman, E., Chiu, C. (2010) The association of stress-coping variables to quality of life among caregivers of individuals with traumatic brain injury. *NeuroRehabilitation,* 27, 49-62. doi:10.3233/NRE-2010-0580	The purpose of this study – to determine which stress-coping variables contribute to quality of life.	N=108 caregivers from Traumatic Brain Injury community based support group & web-based support group in the United States. Care-recipients	Cross-sectional mailed survey. Tools: Modified caregiver appraisal scale COPE – measure coping strategies Interpersonal Support Evaluation List Family Needs Questionnaire World Health Quality of Life Statistics: Sequential multiple	Model accounted for 68% of variance. Emotional social support, social needs, & perceived burden – individual predictors QOL. Emotional support & social needs mediated relationship between burden & QOL.	Non-random convenience sample limits generalizability of results Results cannot be generalized to those who don’t seek support Research design not descriptive correlational – unable to determine causality

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
67. Machamer, J., Temkin, N., Dikman, S. (2002) Significant Other Burden and Factors Related to it in Traumatic Brain Injury. *Journal of Clinical and Experimental Neuropsychology.* 24(4):420-433.	To examine feelings of burden in significant other of mod/severe TBI.	180 relatives Mod/Severe 6 months post injury. Seattle, WA	Cross-sectional Tools: Modified Zarit with positive questions CES-D	SO with ↑burden – negative change in pt, more severe TBI, financial sacrifice	Subjects in seizure prophylactic trial. Majority caring is + experience but a subgroup high burden
68. Nabors, N., Seacat, J., Rosenthal, M. (2002) Predictors of caregiver burden following traumatic brain injury. *Brain Injury.* 16(12):1039-1050. DOI:10.1080/026990502101552285	Investigate the relationship of demographic to cg burden, family needs, & social support & predictors burden.	24 AA 21 White Michigan	Surveys & interviews Tools: Head Injury Family Interview FAD Family Needs Q Non-support scale of Personality Inventory	Household income related to perceived burden Younger caregivers fewer needs met	AA caregivers – limited health care insurance & lower household income Unmet caregiver needs predicted burden

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
69. Hall, K., Karzmark, P., Stevens, M., Englander, J., O'Hare, P., Wright, J. (1994) Family Stressors in Traumatic Brain Injury: A Two-Year Follow-Up. *Archives of Physical Medicine Rehabilitation.* 75: 876-884.	To describe the stressors of TBI caregivers over a 2 year period post injury. 6, 12, 24 months after injury.	51 TBI caregivers over 2 years Santa Clara Valley Med	Longitudinal Study Tools: Subjective Complaint List Disability Rating Scale Risk Psychosocial Assessment FAD Support for Significant Other Perceived Stress Scale Social Readjustment Scale	Caregivers c/o pt-lack of involvement in leisure activities, Fatigue, slowness, forgetfulness, ↑temper outburst, anxiety, self-centeredness ↑ Stress associated-risk of psychosocial hx & ↓ funds	Caregivers i=↑ medication use, substance abuse, ↓ employment, & financial status 22% ↑ financial strain 47% give up jobs at 1 year 33% at 2 years
70. Van Houten, C., Freidman-Sanchez, G., Clothier, B., Levison, D., Taylor, B., Jensen, A., Phelan, S., Griffin, J. (2012/2013) Is Policy Well-Targeted to Remedy Financial Strain among Caregivers of Severely Injured U.S. Service Members? *Inquiry Journal.* 49: 339-351.	Determine factors associated with financial strain in caregivers of severely injured.	Data from FACES study 564 caregivers returned survey.	National Survey Measured leaving the workforce & depleting assets or accumulation of debt.	Fathers debt around $9000 62% depleted assets/debt 41% left workforce-more likely low income	Low intensity needs – help complex task of navigating healthcare & benefits system or emotional support. High needs – cg 4.63 x higher leaving workforce & used 27,576 assets

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
71. Minnes, P., Graffi, S., Nolte, M., Carlson, P. and Harrick, L. (2000) Coping and stress in Canadian family caregivers of persons with traumatic brain injury. *Brain Injury,* 14(8), 737-748.	Purpose to identify stressors of caregivers of TBI patients & identify factors that mediate stress	N= 91 Canada Male= 16 Female=66	Cross-sectional design-participants recruited through mailings Tools: Questionnaire on Resources & Stress Patient Competency Rating Scale F-COPES Statistics: Multiple regression	Lifespan care and personal burden Patient competency rating scale predictor of stress Reframing & spiritual support negatively predictors of stress	Parents prefer greater institutional care than spouse; less personal burden Limitation: small sample size limit generalizability Racial/ethnic groups not identified

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
72. Chwahsz, K. Stark-Wroblewski, K. (1996) The subjective experiences of spouse caregivers of persons with brain injury: a qualitative analysis. *Applied Neuropsychology.*1996; 3:28-40.	Qualitative research to enhance confidence in previous empirical studies.	27 spouses of TBI patients Midwest	Qualitative Essay sample	Themes: "How terrible it is to have a loved one sustain a brain injury" Feeling hopeless, exhausted, Difficulty helping patient cope Change marital relationship Others don't understand	No description of TBI patients Mostly women answered survey- small # answered essay from a bigger study (106) Enigmatic nature of brain injury-many brain injuries go unnoticed
73. Sander, A., Davis, L., Struchen, m., Atchison, T., Sherer, M., Malee, J., Nakase-Richardson, R. (2007) Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *Neurorehabilitation.* 22:9-17.	To determine the relationship between race/ethnicity & caregivers' coping.	195 caregivers 75% white 25% AA/Hispanic 3 treatment sites	Longitudinal study Tools: Ways of Coping Caregiver Appraisal BSI	AA/Hispanic- ↓ education level, annual income, more likely caring extended family	Black/Hispanic – more traditional beliefs- more emotion coping Greater sense of family obligation - ↑ responsibility & more distress

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
74. Lezak, M. (1978) Living with the Characterologically Altered Brain Injured Patient. *Journal of Clinical Psychiatry.* 39:592-598.	To describe living with a loved one when brain injury has altered character.		Report of findings from clinical practice.	Character change- self-centered behavior, impaired capacity for control, social dependency, difficulty planning & organizing; silliness, apathy, irritability	Family members – feel trapped & isolated Spouse cannot divorce with dignity Pt may abuse spouse & children Most family suffer depression Cg - maintain health & vigor

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
75. Mauss-Clum, N., Ryan, M. (1981) Brain Injury and the Family. *Journal of Neurosurgical Nursing.*13(4): 165-169	To describe the effects of brain injury on the family based on the PAVA Brain Injury Rehabilitation Unit.	40 mailed- 30 returned Brain injured- TBI, stroke, cardiac disease Wes t Coast VA	Pilot study-Questionnaire	Inpt needs – info & expectation of pt condition Impt – emotional support, financial counseling & community resources Pt problems - ↓memory, dependency, impatience, Depression , ↓ in motivation & initiative, temper outburst, irritability reported by 50% of families	Long term problems – wives & mothers experienced frustration, irritability& annoyance 50% of wives did not feel had a husband anymore Rehab programs should address emotional or social adjustment along with physical restoration. 1/3 of wives considered divorce – parents do not have that option

Table 2.3: TBI Caregiver Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
76. Arzi, N., Solomon, Z., Dekel, R. (2000) Secondary traumatization among wives of PTSD and post –concussion casualties: distress, caregiver burden and psychological separation. *Brain Injury,* 14 (8), 725-736.	Purpose of this study to assess wives emotional distress & burden with husbands with PTSD or post -concussion. Examine separation-individuation on adjustment	Israel N=20 PTSD N=20 Concussion N=20 Controls	Cross-sectional self-report questionnaires Tools: Caregiver Burden Inventory Symptom Checklist -90 Psychological Separation Inventory Statistics: ANOVA &MANOVA	Women from PTSD & concussion group higher burden than controls; PTSD & PC higher emotional dependence and conflictual independence than controls Wives of PC ↑ emotional burden than PTSD	No data on care receivers Small sample and from clinic populations which limits generalizability

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
77. Griffin, J., Friedman-Sanchez, G., Jensen, A., Taylor, B. Gravely, A., Clothier, B., Simon, A., Bangerter, A., Pickett, T., Thors, C., Ceperich, S., Poole, J., van Ryn, M. (2012) The Invisible Side of War: Families Caring for US Service Members with Traumatic Brain Injury and Polytrauma. *Journal of Head Trauma Rehabiliation,*27(1), 3-13. doi:10.1097/HTR.0b013e3182274260	Identify informal caregivers of veterans with polytrauma and describe variations in caregiver experience	US Veterans received inpatient rehabilitation from 4 centers between 2001-2009 N=564	Cross-sectional mailed surveys Statistical test: Descriptive statistics and Fisher exact x^2 for statistical differences between high, moderate, and low intensity need care recipients	Caregivers: 79% women parent: 62% Spouse:32% 4 years after injury 22% - assistance (ADL & IADL) 25% caregivers > 40 hours/wk. 48% help with IADL 60% sole cg 60%low/mod Work 41% high intensity work	Care intensity did not vary over time Family members most often continue to help veteran manage emotions Non responders to survey may have been significantly different Small number of cases missing data on ADL & IADL Unknown if primary caregiver completed survey
78. Phelan,S., Griffin, J., Hellerstedt, W., Sayer, N,Jensen, A., Burgess, D., van Ryn, M. (2011) Perceived stigma, strain and mental health among caregivers of veterans with traumatic brain injury. *Disability and Health Journal,* 4,177-184. doi:10.1016/j.dhjo.2011.03.003	Goal: describe frequency caregivers experience discrimination and need to cover up & assess feelings of strain, anxiety, isolation, & depression	N=70 caregivers of veterans received care from 1of 4 rehab centers in US	Cross-sectional mailed survey to measure discrimination and stigma involved in care of veteran with traumatic brain Multivariate linear regression	Perceptions of discrimination & stigma by caregiver associated with strain, isolation, depression & anxiety	Stressors may lead to poorer health in caregiver Stigma by association important stressor for caregiver Limitation – causation cannot be attributed Unable to compare responders to non-responders

Table 2.3: TBI Caregiver Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
79. Straits-Troster, K., Gierisch, J., Strauss, J., Dyck, D., Dixon, L., Norell, D. & Perlick, D. (2013) Multifamily Group Treatment for Veterans with Traumatic Brain Injury: What is the Value to Participants? *Psychiatric Services* 64(6):541-546 doi:10.1176/appi.ps.001632012	Evaluate feasibility, acceptability & helpfulness of multi-family treatment for veterans with TBI	8 veterans & 8 family members Bronx & Durham VA	Qualitative Focus Group	Themes: Treatment – explore common struggles & ↓ isolation Build skills - deal w/ TBI Restore relationship w/ vet through communication ↑ understanding interconnection TBI & PTSD	Small sample size Did not include all treatment participants
80. Boschen, K., Gargaro, J., Gan, C., Gerber, G., Brandys, C., (2007) Family interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. *Neurorehabilitation.* 22:19-41	Review of literature on effectiveness of family interventions & present best practices	31 articles identified- 4 brain injury 6 RCT	Anecdotal & descriptive Lack methodological rigor	No evidence to support specific intervention Participants prefer face to face May need longer than 3 months	Research on family interventions after ABI in infancy 3 decades document psych distress in families No "gold standard" to measure stress/burden **Peer support show promise**

Table 2.4: Caregiver Health Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
81. Fengler, A. & Goodrich, N. (1979) Wives of elderly disabled men: the hidden patients. *The Gerontologist.* 19(2):175-183.	Examine special needs of elderly wives caring for husbands with chronic illness.	Volunteers recommend by VNA Workshop/ control 34 men	Interview	Low morale wives- isolation, loneliness, economic hardship, & role overload	6 in low morale & 6 in high morale Small sample
82. Vitaliano, P., Zhang, J. and Scanlan, J. (2003) Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin,* 129(6), 946-972. doi:10.1037/0033-2909.129.6.946	To quantify relationship of caregiving with health problems	N= 45 articles from 1983-2001	Meta-analysis Categories-global self- report of health Physiological variables: immunology, hormones, cardiovascular, metabolic –HCM Statistics: point-biserial correlation	Caregiver 23% higher stress hormone than non-caregiver 15% lower antibody response Greater risk for health problems in caregivers Females reported worse global health	Limitation: Selection bias- all report based on observation & not experiments Premorbid differences between caregivers and non-caregivers not available Reported data may be biased to positive results

Table 2.4: Caregiver Health Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
83. Schulz, R. and Beach, S. (1999) Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study. *JAMA,* 282(23), 2215-2219.	Examine the relationship between caregiving demands and mortality among older spousal caregivers	N=392 caregivers 427 non-caregivers from 4 states: NC, MD, CA, & PA	Prospective observational study- 1993-1998 From HCFA Medicare Enrollment Lists Statistics: Cox regression model	After 4 years 103 spouses died Adjusted for SES, prevalent disease and CHD – caregiver 63% higher mortality than controls	Caregiver experience mental and emotional strain-independent risk for mortality Applies to subset of caregiving population Respite may be needed for physically compromised caregivers
84. Pinquart, M. and Sorensen, S. (2003) Differences between Caregivers and Noncaregivers in Psychological Health and Physical Health. *Psychology and Aging,* 18(2), 250-267. doi:10.1037/0882-7974.18.2.250	Examine differences between caregivers & non-caregivers in physical and psychological health & influences of moderators	N= 84 articles 1987-2002	Meta-analysis	Largest differences in perceived stress, depression, subjective well-being, physical health & Caregivers dementia more depressed	Limitation: small number of studies compared physically frail, nondemented adult with non-caregivers Only examined 7 variables not including SES or duration of caregiving Interventions should allow caregivers more free time due to objective stress findings

Table 2.4: Caregiver Health Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
85. Cacioppo, J., Poehlman, K., Kiecolt-Glaser, Malarkey, W., Burleson, M. (1998) Cellular Immune Responses to Acute Stress in Female Caregivers of Dementia Patients and Matched Controls. *Health Psychology.* 1998; 17(2):182-189.	To investigate whether the stress of caregiving alters cellular immune responses to acute psychological stressors.	27 women caregiver of dementia 37 controls	Experimental	Long term caregiving associated with poorer proliferative response to mitogens & ↓NK response	No evidence of chronic stress altered response to an acute stressor.
86. Donelan, K., Falik, M., & DesRoches, C. (2001) Caregiving: Challenges and Implications for Women's Health. *Women's Health Issues,* 11(3), 185-200.	To examine health impact of providing informal, unpaid care, focusing on women	N=2850 from the national survey of women's health	Descriptive, cross-sectional telephone interview Statistics: bivariate & regression models	48% childbearing age Cg- ↑married Women – disabled reason not working, lower education More caregivers- lower income More health problems-20% depression & unable to get care due to lack of time	Caregivers more likely to have HTN,arthritis,-88% more likely to have chronic illness Lower SES- disproportionate share of caregiving burden Recommend public policy provide more support More education of providers to assess caregivers

Table 2.4: Caregiver Health Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
87. Lu, Y. and Wykle, M. (2007) Relationship between Caregiver Stress & Self-care Behaviors in Response to Symptoms. *Clinical Nursing Research,* 16(1), 29-43. doi:10.1177/1054773806295238	Aim of this study to identify relationship between stress, functional ability, & number of self-care behaviors to symptoms of caregiver of patients with dementia	N=99 dementia caregivers in Midwest city	Correlational, cross-sectional design Tools: Caregiving Hassle Scale 36 Symptom Behavior Checklist CES-D for depression Functional Status Questionnaire Statistics: hierarchal regression	Majority women-white Poor or fair health -30% High stress- poor health & more symptoms including depression, Fatigue, anger Most depressed- not seek help	Limitation: Mostly white-not generalizable Did not assess if behavior appropriate for symptom Health of caregiver is a public health concern – focus on high levels of depression in caregivers
88. Fitting, M., Rabis, P., Lucas, M., Estham, J. (1986) Caregivers for Dementia Patients: A Comparison of Husbands and Wives. *The Gerontologist.*26(3): 248-252.	To examine if gender differences exist for caregivers of dementia patients	54 spouse 28 men 26 women	Descriptive, cross-sectional Interviews Tools: Family Environment Scale Burden Interview MMPI 9 question social network	Females more distressed than men Younger caregivers ↑loneliness & ↑resentment of role	Wives more depressive symptoms & feel more constrained by role Need longitudinal study

Table 2.4: Caregiver Health Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
89. Yee, J. and Schulz, R. (2000) Gender Differences in Psychiatric Morbidity Among Family Caregivers: A Review and Analysis .*The Gerontologist,* 40(2), 147-164.	Examine factors contributing to excess psychiatric morbidity among female caregivers	N=30 empirical research reports from 1985-1998	Narrative approach	Women- more time caregiving than men Women -higher levels of burden, strain, & role conflict Women- more psychiatric symptoms than men	Women less likely to get support & engage in preventative health behaviors As Americans age – future pool of caregivers small Broader gender-family responsive policies & programs needed to decrease psychiatric risk
90. Cannuscio, C., Jones, C., Kawachi, I., Colditz, G., Berkman, L., Rimm, E. (2009) Reverberations of Family Illness: A Longitudinal Assessment of Informal Caregiving and Mental Health Status in the Nurses' Health Study. *American Journal of Public Health.*92:1305-1311.	This study examined the association between caregiving for disabled family member & mental health.	37742 Nurses 4 year change in mental health 1992-1996	Longitudinal analysis from Nurses' Health Study Medical Outcome-SF-36	>36 hours of care to disabled spouse- 6 x more depression or anxiousness symptoms that non-caregiver Disabled parent 2x ↑anxious/ depressed	Estimate 22 million household care for disabled. Caregiving associated with ↑ risk of depress/anxiety 36 hours may be threshold where mental health impairment escalates

Table 2.4: Caregiver Health Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
91. Berg, J.A. & Woods, N.F. (2009) Global Women's Health: A Spotlight on Caregiving. *Nursing Clinics of North America.* 44(3):375-384.	To discuss health issues related to workload and stress as a result of caregiving.	Disproportionate expectations related to caregiving have negative effect on women's health. Caregiving is a global women's health issue. Clinicians & researchers must look beyond burden to assess what fosters women to find gratification in caregiving. Caregiving is physically, emotionally, socially, and financially challenging. Demands outweigh resources.			

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
92. Yang, Q., Cogswell, M., Flanders, W., Hong, Y., Zhang, Z. Loustalot, F., Gillepsie, C., Merrit, R., Hu, F. (2012) Trends in Cardiovascular Health Metrics & Associations with All-Cause and CVD Mortality among US Adults. *JAMA.*307(12):1273-1283. DOI:10.1001/jama.2012.339	To examine trends in cardiovascular health metrics.	NHANES 44959 adults 1988-1994; 1999-2004; 2005-2010	Cross-sectional survey	1.2-2.0% met all 7 metrics 1 or fewer – absolute risk of CVD 6.5/1000 & 3.7/1000 for IHD 6 or more – absolute risk – 1.5/1000CVD & 1.1/1000 for IHD	Consuming healthy diet declined Meeting > number of metric – lower risk of CVD but few met all 7
93. Mosca, L., Mochari-Greenberger, H., Dolor, R., Newby, L., Robb, K. (2010) Twelve-Year Follow-up of American Women's Awareness of Cardiovascular Disease Risk and Barriers to Heart Health. *Circ Cardiovascular Qual Outcomes.* 3:120-127. DOI: 10. 1161.CIRCOUTCOMES.109.915538.	To assess awareness of CVD risk and barriers & evaluate trends.	1142 survey & 1158 contacted on line	Cross-sectional Survey	↑awareness since 1997 but not since 2006 Family caretaking barrier -↑51%	Current cg of adult – 29% of telephone & 24% online 22% phone 31% on-line –cg negative health effect due to ↑stress, exhaustion, less time for self, trouble sleeping, not enough time to spend family/friends

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
4. Mosca, L., Mochari, H., Christian, A., Berra, K., Taubert, K., Mills, T., Burdick, K., Simpson, S. (2006) National Study of Women's Awareness, Preventive Action, and Barriers to Cardiovascular Health. *Circulation.* 113:525-534. DOI: 10.1161/CIRCULATIONAHA.105.588103.	Assess current level of awareness of CVD risk, & if awareness leads to prevention action & barriers.	1008 women Random digit dialing National	Cross-sectional, descriptive Survey	Awareness↑-associated with physical activity & weight loss Barriers: confusion in media, belief health determined by higher power, caretaking responsibilities - 36%	Awareness associated with preventive action Education targeted to racial/ethnic minority women Women **"heart keepers"** of the family Religion hindering cv health needs further research
94. Samuel-Hodge, C., Headen, S., Skelly, A., Ingram, A., Keyserling, T., Jackson, E., Ammerman, A., Elasy, T. (2000) Influences on Day-to-Day Self-Management of Type 2 Diabetes among African-American Women. *Diabetes Care* 23:928-33.	To identify culturally relevant psychosocial issues & social context variables influencing lifestyle behaviors – diet & physical activity.	10 Focus groups with 70 Southern African-American women	Qualitative Study	Themes: Spirituality impt General life stress & cg interfere with disease management Diabetes impact – emotional & physical tired, worry & fear of complications	Interventions to improve self-management should recognize the influence of spirituality, general life stress, multi-caregiving responsibilities, & psychological impact of diabetes

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence					
TITLE & DOI	**PURPOSE**	**SAMPLE/ SETTING**	**METHODS**	**RESULTS**	**DISCUSSION & LIMITATIONS**
95. Lee, S., Colditz, G., Berkman, L., and Kawachi, I. (2003) Caregiving and Risk of Coronary Heart Disease in U.S. Women. *American Journal of Preventive Medicine,* 24(2), 113-119. doi:10.1016/S0749-3797(02)00582-2	Purpose to examine association between caregiving and cardiovascular disease	N=54,412 women from Nurses' Health study in 11 US states	Prospective observational survey-1992-1996 Endpoint – non-fatal MI and fatal CHD RR adjusted for age & multiple risk factors	Total =321 cases of CHD CHD RR =1.82 in women providing ≥ 9 hours of care disable spouse per week	Caring disabled parent or other – no risk Limitations: no information care recipient illness Lack info on duration of caregiving or if women health prior to caregiving
96. Von Kanel, R., Mausbach, B., Patterson, T., Dimsdale, J., Aschbacher, K. Mills, P., Ziegler, M., Ancoli-Israel, S., Grant, I. (2008) Increased Framingham Coronary Heart Disease Risk Score in Dementia Caregivers Relative to Non-Caregiving Controls. *Gerontology.* 54:131-137. DOI:10.1159/000113649	To test hypothesis that Framingham CHD risk score would be higher in dementia caregivers than controls.	64 dementia 41 gender matched controls	Cross-sectional Framingham CHD Score Psychological distress Hamilton Scale for depression	CHD scores higher in caregivers Higher BP made the difference	Clinically relevant difference Clinician may want to monitor caregiver status

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
97. Aggarwal, B., Liao, M, Christian, A., Mosca, L. (2008) Influence of Caregiving on Lifestyle and Psychosocial Risk Factors Among Family Members of Patients Hospitalized with Cardiovascular Disease. *Journal of General Internal Medicine.24(1):93-98.* *DOI:10.1007/s11606-008-0852-1*	To determine prevalence & predictors of caregiver strain & evaluate association cg & CVD lifestyle & psychosocial risk factors	FIT Heart Study Completed 6 month F/U N=263	Longitudinal Tools: Cg Strain Index BDI ENRICHD Social Support Lifestyle Measurements Statistics: regression	Cg more likely women Unemployed, less physical activity, ↑waist circumference Strain ↑in depressed & ↓ social support	Cg of cardiac at risk for CVD morbidity compared non-caregivers
98. Lett, H., Blumenthal, J., Babyak, M., Sherwood,S., Strauman, T., Robins, C., Newman, M. (2004) Depression as a Risk Factor for Coronary Artery Disease: Evidence, Mechanisms, & Treatment. *Psychosomatic Medicine.* 66:305-315.	Review of Literature		Medline 1996-2003 PsychINFO 1872-2003 & bibliography review	Depression – 1.5-2.0 RR onset of CAD 1.5-2.5RR of cardiac morbidity -mortality in existing CAD	Biobehavioral mechanisms – linking depression & CAD Treatment adherence, lifestyle factors, traditional risk factors, alterations in ANS, HPA, platelet activation & inflammation

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
99. Doering, L. & Eastwood ,J. (2011) A Literature Review of Depression, Anxiety, and Cardiovascular Disease in Women. *JOGNN.* 40:348-361. DOI:10.1111/j.1552-6909.2011.01236x	To review current literature regarding depression & anxiety in women with CVD.		Literature review – Pubmed & Cinahl	Women with CVD ↑anxiety & depression than men Depression & anxiety ↑angina, sleep disturbance & family stress	Exercise did not mediate or moderate depression or anxiety Depression & anxiety inversely related to QOL
100. Cohen, B., Marmar, C., Ren, L., Bertenthal, D., Seal, K. (2009) Association of Cardiovascular Risk Factors with Mental Health Diagnoses in Iraq and Afghanistan War Veterans Using VA Health Care. *JAMA.*302(5):489-491.	To examine association of PTSD & other mental disorders with cardiovascular risk factors in IOF/IEF veterans.	303,223 veterans new to VA from 10/2001 to 9/2008	Cross-sectional Data base review	Male & female OEF/OIF veterans with mental health diagnoses – significantly > rates of tobacco use, HTN, Hyperlipidemia, & obesity	24% PTSD 53% depression 29% anxiety disorder 22% alcohol abuse 10% substance use

Table 2.5: Cardiovascular Health and Women Caregivers Table of Evidence

TITLE & DOI	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
101. Saban, K., Hogan, T., DeFrino, D., Evans, C., Bauer, E., Pape, T., Steiner, M., Proescher, E., Vlasses, F., & Smith, B. (2013) Burnout and coping strategies of polytrauma team members caring for veterans with traumatic brain injury. *Brain Injury.* 27(3):301-309. DOI:10.3109/02699052.2012.743183	Examine extent of burnout among polytrauma team & identify coping strategies	233 team members	Cross sectional Tool: Maslach Burnout Inventory	24% high levels of emotional exhaustion >50% time caring – more exhaustion	Themes: connect with others, promote healthy lifestyle, pursue outside interests, manage work environment, positive thinking

Figure 2.1: Classifications, Definitions, Prevalence, and Diagnosis of Traumatic Brain Injuries and Comorbidities

Syndrome	Determining Severity			Prevalence	Diagnosis	Signs/ Symptoms	Discussion
	Glasgow Coma Scale (total score)	Loss of consciousness (duration)	Posttraumatic amnesia (duration)				
Mild TBI[8,13] (concussion)	13-15	< 1 hr.	< 24 hrs.	**Overall:** 12% **Within TBI group:** 231,386 (82.4%)[10]	VA TBI screen Biomarkers Diffusion tensor imaging (DTI)	Dizziness, light sensitivity, memory problems, sleep problems, Headache, irritability	Outpatient mTBI may inflate affective symptoms long after concussive symptoms resolved
Moderate TBI[8,13]	9-12	1-24 hrs.	24 hrs. to < 7 day	**Overall:** .01% **Within TBI group** 22,815 (8.1%)[10]	MRI/CT	Coma for 1 day	Inpatient with rehab Removed from combat
Severe TBI[8,13]	3-8	> 24 hrs.	7 days or more	**Overall:** .001% 2,831 (1.0%)[10]	MRI/CT	Coma for greater than 1 day	Inpatient with rehab Removed from combat
Persistent Postconcussive Symptoms (PPCS)[15]	Persistent symptoms lasting > than 3 months following a mild TBI with three or more of the following: headache, dizziness, fatigue, irritability, concentration or memory problems, & heightened reactivity to stress, emotions, or substance use				PHQ-15 VA 5-part TBI Screen Neurobehavioral Symptom Inventory		Outpatient Overlap between mTBI symptoms & PTSD
Posttraumatic Stress Disorder (PTSD)[32]	PTSD is a pattern of symptoms that develop as a result of witnessing or experiencing a traumatic event or stressor that causes extreme horror, fear, or helplessness. Three main clusters of symptoms: re-experiencing, avoidance, and hyperarousal. Symptoms need to be present for at least 1 month & cause significant distress in occupational or social functioning to qualify for diagnosis.			**General:** 11-14% **TBI** 33.3-68.2% mTBI-RR2.1[20]	PTSD Checklist (PCL)	Sleep problems; irritability; nightmares; avoidance; hypervigilance, emotional numbing	Outpatient

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Chapter 3

Theoretical Framework

Researchers of the caregiving experience have frequently framed their investigation using stress and coping models.[1] The phenomenon of stress has both cognitive and physiologic components, which are well suited to an integrative science approach utilizing interdisciplinary models.[2] The theoretical framework for this proposed study will be the "Unifying Model of the Stress Process" by Cohen, Kessler, and Gordon.[3] The Cohen model will be adapted by incorporating the neurobiology of McEwen's stress theory of allostasis and allostatic load in order to understand the influences of stress on cardiovascular health.[4] This proposed study will examine both the psychological response and the biological response to stress in female caregivers of veterans with traumatic brain injury.

Brief Review of Stress Theories

There are two basic theoretical approaches to explain the concept of stress. The response-oriented theory of stress describes the physiological responses to stress. This approach is exemplified in Selye's General Adaptation Syndrome and in McEwen's theory of allostasis The transaction oriented theory of stress was developed by Richard Lazarus and describes the psychological and emotional responses to stress as transactions between the individual and the environment.[5] Cohen incorporates both of these approaches in the Unifying Model of the Stress Process. Each theory will be described in detail (See Table3.1).

Hans Selye made popular the "fight or flight" response to stress. Stress is defined as "*the nonspecific response to noxious stimuli"* (Rice,2012, page 11).[5] When faced with a stressor, the sympathetic nervous system and the adrenocortical system are activated allowing for an adaptive reaction in the body. The entire stress process including the threat and the individual's reaction to it is called the general adaptation syndrome (GAS).[5] There are three distinct stages: the alarm stage, resistance stage and the exhaustion stage. In the alarm stage, the sympathetic nervous system and the adrenocortical system are activated so that the individual can either fight or flee from the stressor. In the stage of resistance, the body's homeostasis is restored when adaptation is sustained. If the stress persists, the stage of exhaustion follows and illness or death ensues.[4] This theory is limited in that it does not account for individual differences in reaction or address the role of perception and interpretation of the stimulus.[5]

Neuroscientist Bruce McEwen builds on the GAS to include the concept of allostasis as opposed to homeostasis.[4] Allostasis is a dynamic process by which the body responds to daily events and achieves new levels of homeostasis in response to chronic challenges. Stress refers to responses that are costly in terms of arousal of physiologic systems and elicitation of harmful behaviors. Behavioral responses, including vigilance and helplessness, have biological counterparts. The main hormonal mediators of the stress response are epinephrine and cortisol, both of which can have protective and damaging effects on the body[5]. In an acute challenge, release of these hormones allows the body to adapt to challenges. Chronically increased allostasis can produce wear and tear on the regulatory system, which creates an allostatic load. In allostatic load, the allostatic processes either fail to shut off or fail to engage rendering the physiological systems unable to adapt leading to disease; allostatic load can be viewed as the physiological cost of chronic stress to the body.[6] Physiological indicators of allostatic load include systolic and diastolic blood pressure, total cholesterol and glycosylated hemoglobin (HbA1c). High allostatic load can lead to cardiovascular disease.[7]

Lazarus developed and tested the transactional theory of stress and coping, focusing on the individual's psychological responses to stress. In this theory, stress is viewed as a transaction between the person and his/her environment. Psychological stress *is "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being"* (Lazarus & Folkman, 1984, page19).[8] Central to this theory is the concept of appraisal – an evaluation of the significance to the individual of an antecedent event or stressor. Stress can be categorized by an individual as harmful, diminishing, threatening, challenging, or as benign. Primary appraisals involve the individual's considering what any goals, values, or core beliefs may be at stake. Secondary appraisals involve evaluation of possible actions to correct the troubled person-environment relationship. [9] Coping is "*the effort to manage the psychological stress"* (Lazarus, 2009, 2012, page205).[9] Two types of coping are problem focused and emotion focused coping.[9]

Cohen's "Unifying Model of the Stress Process" (UMSP) model, combined with McEwen's theory of allostatic load, has been selected for the proposed study because it integrates both the psychological and biological responses to stress. In the UMSP model, when confronted with an environmental demand or stressor, individuals appraise: 1) the degree to which a demand poses a threat, and 2) if they have the resources to cope with the threat. If the demand exceeds the coping resources, the individual will perceive the situation as stressful. This stress can lead to negative affective, behavioral, or physiological responses. These negative states can put the individual at risk for cardiovascular disease.[3]

Combined Unifying Model of the Stress and Allostatic Load Theories Applied to Caregiving

Both the biological and psychological responses to the demands of caregiving for veterans with traumatic brain injury can be observed utilizing the Cohen's UMSP (Figure 3.1). For the proposed study, caregiving demands are driven by the level of the veteran's disability or symptomatology and the caregiving tasks required to maintain the veteran in the community. The objective demands of caregiving can be measured by observing the types and amount of care provided. Veteran characteristics, including cognitive impairment and behavioral problems, will influence demands on the caregiver. Providing emotional support can also burden the caregiver. Subjectively, if the caregiver does not have the resources to meet the demands, they can perceive themselves to be stressed.[1]

In the next stage of the model, the caregiver appraisal of stress can result in a negative emotional state such as depression or anxiety. These emotional states may trigger behavioral or physiological responses that can lead to disease.[3] McEwen's theory of allostasis provides additional details of the behavioral and physiological responses to stress. In response to stress, the individual can engage in health damaging or health promoting behaviors associated with cardiovascular disease. For example, health promoting behaviors might include not smoking, no or moderate drinking, a diet rich in fresh fruits and vegetables and low in saturated fats, and regular exercise. Chronic activation of the neural and neuroendocrine mediators can affect the cardiovascular system putting the individual at risk for diseases including hypertension, stroke, or myocardial infarction.[10] The final outcome for this study will be increased cardiovascular risk or allostatic load in the caregiver. Markers of allostatic load include elevations in blood pressure, increased cholesterol or low high density lipoproteins (HDL), and increased blood sugar.[10] A cardiovascular risk matrix based on a composite score of individual risk markers including blood pressure, cholesterol, glucose, diet, weight, exercise, and smoking will be used to determine allostatic load.

Summary

Physical health outcomes are an area that is underdeveloped in caregiver research. Cohen's UMSP, combined with McEwen's Allostatic Load theory, provides an interdisciplinary view of stress and integrates both the psychosocial and physiological aspects of the stress response. This model provides a comprehensive understanding of stress in the caregiver by including affective, behavioral, and physiological responses to stress. The theory of allostasis and allostatic load incorporates the most recent research detailing the physiological effects of stress on the brain and its relationship to the development of chronic disease.

Figure 3.1: Integrated Stress Process and Allostasis Model

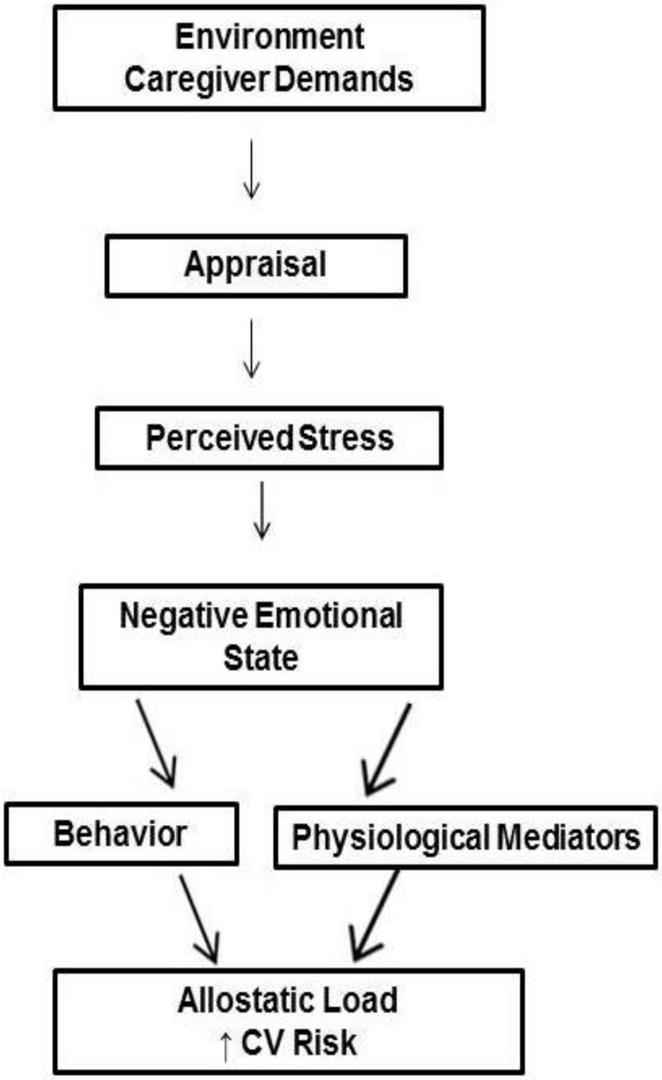

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Table 3.1: Stress Theories Development

Scientific View	Conceptualization of Stress	Key Concepts
Response Based (Selye1956, 1983)	Stress is the nonspecific response to noxious stimulus. The physiological response is always the same regardless of the stimulus – the general adaptation syndrome (GAS)	• Emergency reaction of the sympathetic nervous & adrenocortical systems • Homeostasis – the stability of the physiologic systems that maintain life (ie: pH) • 3 Stages – Alarm, Resistance, & Exhaustion stage • Does not account for individual differences in reaction (ie: gender) or address role of perception & interpretation of stimulus
Transaction Based (Lazarus & Folkman, 1984; Lazarus, 1991)	Stress is experienced when the demands of a situation tax or exceed a person's resources and some type of harm or loss is anticipated.	• Causal antecedents – person & environmental variables • Appraisal – harm & loss; threat, or challenge • Primary appraisal – What is at stake? Any goals, important relations or core beliefs • Secondary appraisal – What can be done about the troubled person-environment relationship • Coping – constantly changing cognitive & behavioral efforts to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person. • Emotions – flow from the way we appraise what is happening in our lives-reflect the fate of our goal striving
Unifying model of stress process (Cohen, 1997)	Stress is a process in which environmental demands tax or exceed the adaptive capacity of an organism	• Environment – events or experiences that are associated with substantial adaptive demands • Psychological – Individuals' subjective evaluations of ability to cope with demands • Biological – activation of physiological systems that are modulated by both the psychological and physiological demanding condition
Response Based Allostasis & Allostatic Load (McEwen, 1993; 2007)	Allostasis – physiologic systems within the body fluctuate to meet demands from external forces Allostatic load – cost of chronic exposure to fluctuating or heightened neural or neuroendocrine response resulting from stressful challenges.	• Behavior – interpretation of an reaction to challenge • Biological responses – neural and neuroendocrine mediators effect CV system with CV disease outcome • Individual differences

Chapter 4 Research Methodology

Problem Statement

Since September 11, 2001, over 2.7 million Americans have served in the conflicts in Iraq and Afghanistan.[1] Posttraumatic Stress Disorder (PTSD) and traumatic brain injury (TBI) have been labeled the “invisible wounds” of modern warfare.[2,3] The use of improvised explosive devices (IED) by the enemy have made blast related TBI, particularly mild TBI (mTBI) the “signature” wound of the current conflicts.[4] Neurobehavioral symptoms, TBI and PTSD in post 9/11 veterans may lead to long term health effects and resultant lifelong caregiving needs.[2,5,6]

There is substantial overlap in neurobehavioral symptoms of mTBI, PTSD, and depression. Often the family caregiver is responsible for managing these symptoms.[7] Studies to date have focused on moderate to severe TBI in the in-patient and rehabilitation setting. Now veterans are reintegrating into the community, but there is little systemic evidence regarding the challenges faced by both patients with mTBI and their families. To date, there have been no nursing studies examining best practices of the care of the veteran with invisible wounds of war in the home setting.

Research regarding TBI and PTSD has focused on the disease specific needs of returning service members but the needs of caregivers remains largely overlooked.[8] Women, primarily wives and mothers, are the primary caregivers of veterans with invisible wounds.[5] As they put their own concerns behind the needs of their veteran family member, these women often sacrifice their own physical and emotional health.[8] Caregivers of post 9/11 veterans report symptoms of depression, anxiety, isolation, and financial strain indicative of significant burden and strain.[9] Caregiving responsibilities have been cited as an impediment to heart health.[10] One underdeveloped area of caregiver scholarship is research that examines caregiver physical and behavioral health outcomes.[11]

Problem

A review of the empirical literature found that female caregivers are at increased risk for physical and mental health problems.[11] Caregiving demands are often physically, emotionally, socially, or financially challenging.[12] These demands often outweigh resources which results in stress.[13] This stress can lead to lifestyle behaviors that put women at risk for cardiovascular disease.[14] Studies to date have focused on the psychosocial aspects of caregiver burden.[11] Research examining physical health outcomes, in particular cardiovascular risk, is limited.[15] Therefore, the purpose of this descriptive, exploratory mixed method study was to examine the effects of caregiving on cardiovascular health in female caregivers of post 9/11 veterans with invisible wounds of war (TBI or PTSD). Specific aims of the quantitative survey include:

1. Describe the severity of emotional burden and practical burden in female caregivers of veterans with TBI or PTSD.
2. Describe the correlation of caregiver burden to the type of neurobehavioral symptoms (somatic, affective, or cognitive) in veterans with TBI or PTSD. *Hypothesis: Caregiver burden will be more highly correlated to veterans' affective symptoms compared to cognitive or somatic/sensory symptoms.*
3. Explore the relationship of psychobehavioral caregiver variables to cardiovascular health in female caregivers of veterans with TBI or PTSD. *Hypothesis: Caregiver emotional burden, practical burden, depression, anxiety, perceived stress, and lack of social support will be correlated with poor cardiovascular health.*

   Specific aims of the qualitative interviews include:

4. Explore the experience of caregivers of veterans with invisible wounds of war as related to cardiovascular health.
5. Identify the barriers and facilitators of heart health self-care as perceived by the caregivers.

Design

This descriptive, cross-sectional, exploratory mixed method study used a convergent design with merged integrated results.[16] The quantitative survey examined the relationship between emotional and physical caregiver burden, perceived stress, depression, anxiety, social support and cardiovascular risk in mothers and wives caring for post 9/11 veterans with TBI or PTSD. The goal of the qualitative interviews was to understand the caregivers' experience and stressors as related to cardiovascular health.

Sample and Setting

A convenience sample of 20 mothers and wives who are primary caregivers of veterans with TBI or PTSD was enrolled. Participants were recruited from community-based veteran organizations and through the social media platform Facebook. [17]

Inclusion criteria for **caregivers**:

1. Mother or wife who self-identifies as the primary caregiver for a veteran with TBI or PTSD.
2. English-speaking (Instruments are validated in English)

Inclusion criteria for **veterans**:

1. Veteran separated from the military after October 2001 and served in Iraq or Afghanistan.

Seven participants who had completed the online survey participated in the semi-structured interview. Interviews were done by telephone or in person.

Quantitative Instruments

Eight self-report instruments were included in the on-line survey. The instruments are listed below:

Independent Variables:

1. The Neurobehavioral Symptom Inventory -22: Measures postconcussive symptoms of veterans.
2. The Oberst Caregiving Burden Scale (CBS): Measures caregivers'' practical burden.
3. The Involvement Evaluation Questionnaire (IEQ): Measures caregivers' emotional burden.
4. The Perceived Stress Scale (PSSS): Measures perceived life stress.
5. The Patient Health Questionnaire (PHQ)-9: Measures depressive symptoms.
6. The Generalized Anxiety Disorder Screener (GAD)-7: Measures symptoms of anxiety.
7. The Medical Outcome Study: Social Support Survey (MOS-SSS): Measures dimensions of social support.

Dependent Variable:

1. The American Heart Association (AHA) "Life's Simple 7: Measures self-reported overall cardiovascular health.

Description of Instruments:

Neurobehavioral Symptom Inventory – 22 (NSI): The NSI is a 22 item self-report inventory of symptoms commonly observed among patients with TBI. In the NSI, respondents indicate the effect of 22 symptoms on their functioning within the previous 30 days. The NSI utilizes a 5-point Likert scale, ranging from "None" to "Very Severe," with higher scores indicating more severe symptoms. Acceptable internal consistency and external validity was reported in a study of 500 OEF/OIF veterans. The NSI demonstrated high internal consistency for the comprehensive scales (total α =0.95, subscale α = 0.88 to 0.93).[18] Cronbach alphas for each of the subscales range from 0.88 to 0.92. The NSI was compared to the Beck Anxiety

Inventory BAI), Beck Depression Inventory (BDI) and the Posttraumatic Stress Disorder Checklist – Military Version (PCL-M) to evaluate external validity. Correlations ranged from 0.41 for NSI-TBI to 0.67 for NSI-PCL-M. Veterans who experienced mTBI rated all NSI symptoms significantly higher than controls. Correlations of measurements for PTSD, anxiety, and depression with the NSI were of similar magnitudes.[18]

The Oberst Caregiver Burden Scale (OCBS): The OCBS measures the practical burden of caregiving. It has separate scales for time spent in caregiving (demand) and amount of difficulty associated with each of the 15 frequently reported caregiving tasks. For each task, five point response scales are used for time (*none* = 1 to a *great amount* = 5) and for perceived level of difficulty (*not difficult* = 1 to *extremely difficult* = 5). Higher scores represent more perceived practical burden.[19] Cronbach alphas of 0.90 for time and 0.94 for difficulty supported internal reliability in caregivers of stroke survivors. Item total correlations ranged between 0.38 and 0.74 for time subscale and between 0.55 to 0.78 for difficulty scale.[19]

The Involvement Evaluation Questionnaire (IEQ): The IEQ is a self-report questionnaire with 31 items that was developed to measure caregiver worries, coping, and emotional burden. Responses are scored on a 5 point Likert scale (never, sometimes, regularly, often, always), with higher scores indicating greater emotional burden. The sum score is based on 27 items and comprises four subscales (tension, supervision, worrying, and urging). Cronbach's alpha for the sum score was 0.89 and for Cronbach's alpha for the subscales ranged from 0.73-0.84. Low correlations were found between the Involvement Evaluation Questionnaire and the Family Assessment Device subscales (r=-0.29-0.19), which demonstrates that emotional burden is different from a stable construct such as family functioning. This tool was tested in caregivers of patients with chronic acquired brain injury.[20]

Perceived Stress Scale (PSS): The PSS is a 14-item measure of the degree to which situations in one's life are appraised as stressful. The PSS is designed to tap the degree to which respondents found their lives uncontrollable, unpredictable, and overloaded. Higher scores are indicative of higher levels of perceived stress. Coefficient alpha reliability was 0.85 and retest correlation was .85.[21]

Patient Health Questionnaire (PHQ-8): The eight-item Patient Health Questionnaire (PHQ-8) is used to assess depressive symptoms. The PHQ-8 consists of eight of the nine criteria on which the DSM-IV diagnosis of depression is based. The ninth question assesses suicidal or self-injurious thoughts and is omitted for internet or telephone research when adequate intervention is not possible.[22] Items are scored on a scale of 0-3 based on the number of days in the past two weeks that respondents had experienced a particular depressive symptom. Scores range from 0-24, with higher scores indicating greater symptom severity and frequency. A PHQ-8 score of $\geq$10 has an 88% sensitivity and 88% specificity for major depression.[23] Cronbach's alpha of 0.89 has been reported in a primary care study.[24]

Generalized Anxiety Disorder Screener (GAD-7): The Generalized Anxiety Disorder Screener (GAD-7) is a seven item self-report questionnaire that measures anxiety. Acceptable reliability and validity was reported in primary care patients. The GAD-7 items describe the most prominent diagnostic features of the DSM-IV diagnostic criteria for generalized anxiety disorder. Subjects are asked how often in the last 2 weeks they have been bothered by each of the 7 core symptoms of generalized anxiety. Items are rated on a scale of 0-3 and scores range from 0-21, with higher scores indicating greater anxiety. Scores of $\geq$ 5, $\geq$ 10, and $\geq$ 15 represent mild, moderate, severe anxiety symptoms respectively.[25] The internal consistency of the GAD-7 was excellent (Cronbach α = .92). Test-retest reliability was good (intraclass correlation =0.83).[26]

The Medical Outcome Study Social Support Survey (MOS-SSS): The MOS-SSS is an instrument that consists of 19 items with 4 subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. Each subscale score is an average of the scores on the subscale. An overall support index is calculated by averaging the scores for all items. These support measures are distinct from structural measures of social support and from related health measures. The reliability for all subscales is strong (alpha > 0.91 for all subscales). Acceptable reliability, content validity, and construct validity for this scale was reported in patients with chronic conditions.[27]

American Heart Association (AHA) Life's Simple 7: Life's Simple 7 (LS7) is a metric developed by the AHA in which ideal cardiovascular health is defined by the presence of healthy behaviors and health factors.[28] Using an online format, participants are asked to report information regarding smoking patterns, blood cholesterol and blood sugar levels, blood pressure, weight, physical activity level, and dietary intake. Each of the Life's Simple 7 components can be categorized as ideal, intermediate, or poor. While no psychometrics of the LS7 have been published to date, several recent studies have reported its use in ongoing longitudinal studies which examined cardiovascular health on the basis of LS7 score and incidence of stroke, cognitive impairment, and diabetes.[29-31] In the stroke study, a one point higher LS7 score was associated with an 8% lower risk of stroke.[29] Scores on the LS7 in the intermediate and high ranges for cardiovascular health (scores 7-14) were associated with a substantially lower incidence of cognitive impairment.[30] Adoption of as few as two or three LS7 goals is associated with a lower risk of diabetes.[31]

Summary

In this study, seven instruments were used to examine burden in the caregiver. The NSI was used to examine the characteristics of the veteran that functioned as stressors for the caregiver. The OCBS and the IEQ examined practical and emotional burden for the caregiver. The PSS gave an indication of whether or not the level of burden was considered stressful. The MOS Social Support Survey examined whether or not the caregiver demonstrated help seeking behaviors. These variables were examined in relation to the dependent variable of cardiovascular health as measured by LS7. Each LS7 score was given a point score of 0, 1, or 2 to represent poor, intermediate, or ideal health, respectively.[32]

Qualitative Interview

The semi-structured interview guide addressed the following research questions:

1. What was the caregivers' experience in caring for veterans with invisible wounds of war?
2. What were the caregivers' perceptions of stressors, facilitators, and barriers to cardiovascular self-care?

Procedures

Quantitative Survey

Approval from the UCLA institutional review board was obtained prior to the start of data collection. Participants were recruited via Facebook, study website, and community veterans' organizations. Interested participants completed an on-line screening survey to determine eligibility. For on-line screening, qualifying participants accessed the surveys from a direct link embedded in an invitation e-mail. The invitation contained all the elements of consent as required by the UCLA IRB. All elements of the consent were included in the surveys. RedCAP, a secure web application designed exclusively to support data capture for research studies, was used to post the screening survey as well as the study instruments.

Qualitative Study

Participants who had agreed to be contacted for further studies on the screening survey were invited to participate in the qualitative interview. Interviews were conducted using a Semi-structured interview guide (Appendix A). Interested participants were sent a consent form via e-mail prior to starting study procedures. Once the consent was completed, the principal investigator scheduled a time for the interview. Interviews were conducted in person or by telephone. Interviews were recorded and audio files were transcribed on password protected device. Interviews were transcribed by the principal investigator.

Analysis

Quantitative Survey

Each aim required statistical analysis. Measures of central tendency were used to describe the demographics of caregivers and veterans with TBI or PTSD (Appendix B). For each instrument, internal consistency was measured by Cronbach's alpha. In addition, distribution of scores for each instrument was evaluated for normality.

Aim 1: *To describe the severity of emotional burden (as measured by the IEQ) and practical burden (as measured by the OCBS) in female caregivers of veterans with TBI.*

Measures of central tendency were used including mean, median, standard deviations and ranges for each item of the burden subscale and the difficulty subscale of the OCBS. The same measures of central tendency were used for the total summary score of the IEQ and for e*ach subscale (i.e., tension, supervision, worrying, and urging).*

Aim 2: *To evaluate the relationship of caregiver burden (as measured by the OCBS and the IEQ) to type of neurobehavioral symptoms (somatic, affective, or cognitive as measured by respective subscales of the NSI) in veterans with TBI.* Hypothesis: *Caregiver emotional burden will be more highly correlated to veterans' affective symptoms than to veterans' cognitive or somatic/sensory symptoms.*

Mean scores, standard deviations and confidence intervals were calculated for each subscale of the NSI (somatic, affective, or cognitive). The relationship of practical burden (as measured by the OCBS) to each subscale of the NSI (somatic, affective and cognitive) was evaluated using Pearson's correlations. The same procedure was used to evaluate the relationship of emotional burden (as measured by the total score of the IEQ) and each subscale of the NSI.

3. **Aim 3:** *To identify psychobehavioral caregiver variables that are associated with cardiovascular health in female caregivers of veterans with TBI.* *<u>Hypothesis:</u>* *Caregiver emotional burden, practical burden, depression, anxiety, perceived stress, and lack of social support will be correlated with poor cardiovascular health.*

Bivariate correlations of LS7 with psychobehavioral variables (OCBS, IEQ, PSS, GAD-7, PHQ-8, and MOS-SSS) and caregiver demographics (age, income, educational level, length of time caregiving, kinship, and income) using Pearson's R was conducted.

<u>Qualitative Interview</u>

Aim 4: *Explore the experience of caregivers of veterans with invisible wounds of war as related to cardiovascular health.*

Aim 5: *Identify the barriers and facilitators of heart health self-care as perceived by the caregiver.*

Content analysis procedures were used to analyze the qualitative interview specific aims.

Threats to Validity

Study validity is an important concern in the research process as a measure of truth or accuracy of a claim. Validity is important when considering if the findings of a study are sufficiently valid to add to the evidence base for practice. Four types of validity were considered in the design of the study: statistical conclusion validity, internal validity, construct validity, and external validity. Not all threats to validity can be controlled but elements were added to the study design in an attempt to mitigate the threats.

<u>Statistical conclusion validity</u>

Statistical validity may be threatened by having too small a sample size or by missing data. The researcher reviewed all data and contacted study participants to complete missing data. Violation of assumptions of statistical tests may render results inaccurate. Study design was reviewed by a statistician to validate the sample plan. Statistical errors may be made by not coding variables correctly and again review by statistician helped prevent this problem.

Internal Validity

The greatest threat to internal validity was the degree that the variables test what is intended. Although the tools used in this study have been tested in a variety of patient populations such as dementia, stroke, acquired brain injury, and cancer, they have not been tested in the caregivers of veterans or in the TBI or PTSD populations. Internal consistency was calculated for all instruments in this study in order to validate instruments in this population. The use of a cross sectional design limited our ability to make inferences about changes in variables over time.

Construct Validity

Construct validity examines the fit between the instruments and the theoretical constructs.[33] Two theoretical frameworks were used in this study in order to control for the threat of inadequate explanation of constructs. Several measures of caregiver burden and emotional response to caregiving were used in order to control for mono-operation bias. Measuring anxiety and depression validated the measure of emotional burden and further defined the construct.

External Validity

External validity is concerned with the extent to which the study findings can be generalized beyond the population. Selection bias limited the generalizability of this study. Self-report of caring for a veteran with TBI or PTSD might have resulted in caregivers who were most burdened responding to the invitation. On-line survey method limited participants to those who are computer literate and have ready access to a computer and online capability. To avoid this threat, participants were offered in person or telephone surveys. External validity will be increased by repeated measures or replicating findings in a larger, multicenter study.

Summary

This study described the psychobehavioral variables that were associated with cardiovascular health in women who identify themselves as primary caretakers of a veteran with TBI or PTSD*.* The instruments selected for this study have been psychometrically validated in caregiver research. Conduct of an a priori power analysis limited the threat to statistical conclusion validity. Use of established theories of stress controlled for threats to construct validity. While self-selection to participate in an on-line study limited the generalizability of the study, this method allowed for a greater number of subjects to enroll in a short period of time limiting the threat to statistical conclusion validity. Although validity was limited to this sample, results of this study added to understanding the phenomenon of caregiver burden.

Ethical Aspects of Proposed Research

University of California, Los Angeles IRB approval was obtained. All study personnel who had access to the data or to participants completed human subject protection training before beginning to participate in the study. All participants had the study explained to them and had all questions answered before consenting to participate in the study. All elements of the consent were on-line and participant agreed to all elements before being directed to the study questionnaires. All electronic data was encrypted and password protected. Data was stored on a secure network server. All data was stripped of personal identifiers.

All participants had the qualitative study explained to them and had all questions answered before consenting to the study. All elements of the consent were on-line and participants agreed to all elements prior to the initiation of the qualitative study procedures. The interviews were recorded on a password protected device. Audio files were transcribed. All identifiers such as names and places were deleted from the transcription. Audio files were transferred onto a password protected computer, which is be stored in a locked area. The study written transcripts (computer and paper copies) are kept in a locked storage area.

Inclusiveness of samples: As women are most impacted by the caregiving role, the study sample was restricted to mothers and wives caring for veterans with traumatic brain injury or PTSD. Adult men and children were excluded from the study as they are not the principle caregivers of veterans.

Potential Risks: This study entailed minimal risk. Subjects may have experienced transient emotional distress or anxiety while completing questionnaires. All subject records were labeled with subject ID only limiting the risk of a loss of privacy.

Potential Benefits: Participation in the research may have provided insight regarding cardiovascular risks for the participants. The results of the research may benefit the community by providing insight into the needs of caregivers of veterans with traumatic brain and the development of community programs.

Conclusions

This study was designed to describe the effects of caregiving on heart health for female caregivers of veterans with invisible wounds of war. Results of this study will be used to identify determinants of cardiovascular risk in caregivers of veterans TBI or PTSD. By differentiating between practical and emotional burden, or lack of social support, targeted intervention studies can be developed. Results may also show the efficacy of LS7 as an effective screening tool of cardiovascular risk to be used by clinicians and caregivers to develop a personal cardiovascular health promotion program. The qualitative interview identified common themes of the caregiving experience as related to heart health self-care.

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CHAPTER 5

RESULTS

The purpose of this study was to examine the effects of caregiving on cardiovascular health in mothers and wives caring for post 9/11 veterans with Traumatic Brain Injury (TBI) or Post Traumatic Stress Disorder (PTSD). The study examined both the biological and psychological responses to stress by integrating “Cohen’s Unifying Model of the Stress Process” and McEwen’s Theory of Allostasis. The design of this descriptive, mixed methods study was a sequential, exploratory design with convergent results. The quantitative, online survey examined the relationship between emotional and practical caregiver burden and psychobehavioral caregiver variables to cardiovascular health in the caregivers. Specific aims of the quantitative survey include:

6. Describe the severity of emotional burden and practical burden in female caregivers of veterans with TBI or PTSD.
7. Describe the correlation of caregiver burden to the type of neurobehavioral symptoms (somatic, affective, or cognitive) in veterans with TBI or PTSD. *Hypothesis:* *Caregiver burden will be more highly correlated to veterans’ affective symptoms compared to cognitive or somatic/sensory symptoms.*
8. Explore the relationship of psychobehavioral caregiver variables to cardiovascular health in female caregivers of veterans with TBI or PTSD. *Hypothesis:* *Caregiver emotional burden, practical burden, depression, anxiety, perceived stress, and social support will be correlated with poor cardiovascular health.*

The goal of the qualitative interview was to understand the caregivers’ experience and stressors as related to cardiovascular health. Specific aims of the qualitative interview include:

4. Explore the experience of caregivers of veterans with invisible wounds of war related to cardiovascular health.

5. Identify the barriers and facilitators of heart health self-care as perceived by the caregiver.

Quantitative Surveys

The goal of the quantitative study was to examine the relationship between practical and emotional burden, perceived stress, depression, anxiety, social support and cardiovascular risk in mothers and wives caring for post 9/11 veterans with TBI or PTSD. The online survey was composed of eight instruments. Veteran symptoms were measured by the Neurobehavioral Symptom Inventory (NSI). The Oberst Caregiver Burden Scale (OCBS) was utilized to measure practical burden and the Involvement Evaluation Questionnaire (IEQ) was utilized to measure emotional burden in the caregiver. Caregiver stress was evaluated using the Perceived Stress Scale (PSS-14); caregiver depression was evaluated using the Patient Health Questionnaire (PHQ-8); and caregiver anxiety was evaluated using the General Anxiety Disorder Screener (GAD-7). Social support was measured using the Medical Outcome Study: Social Support Survey (MOS-SSS). Cardiovascular health was measured using the American Heart Association Life Simple 7.

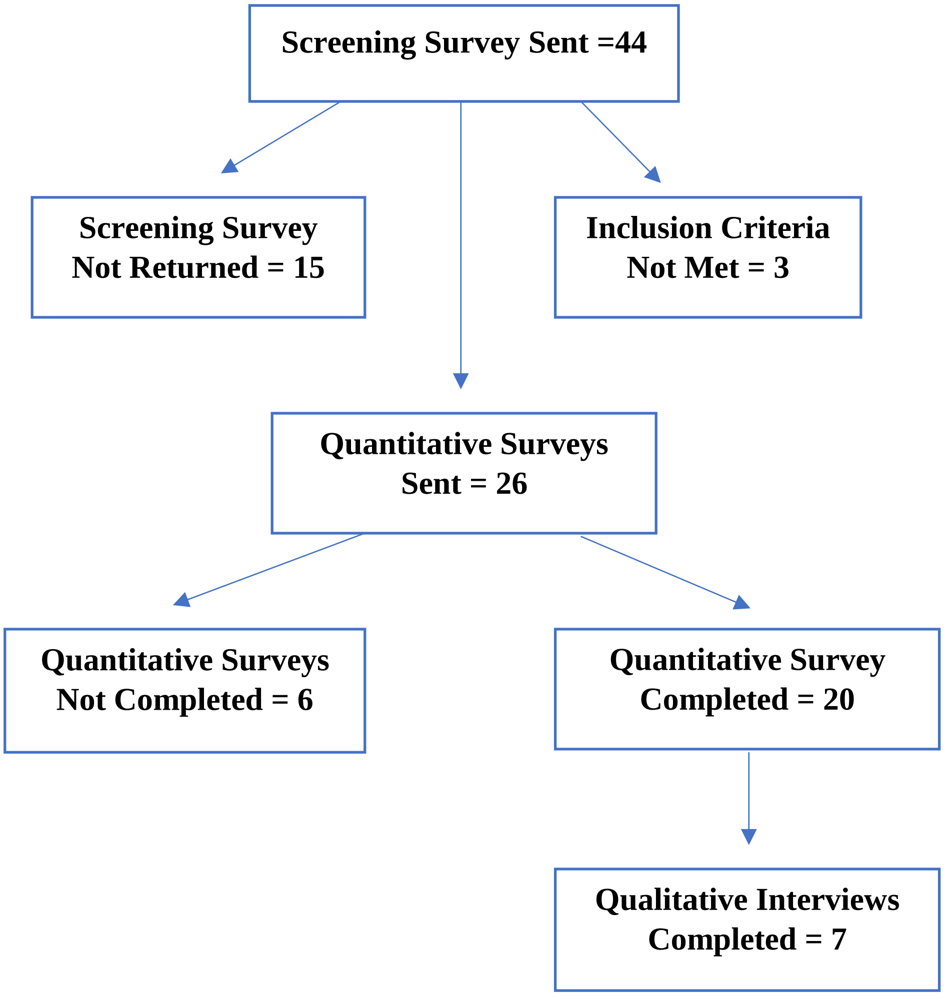
The results of the quantitative survey will be organized into 4 sub-sections: sample recruitment, descriptive results, statistical results, and summary. Cronbach's alpha was used to evaluate internal reliability for each instrument. Correlates of cardiovascular health were analyzed using bivariate analysis.

Sample Recruitment

Participants were recruited by flyer posted on two veteran caregiver Facebook pages or at veteran meetings in the community. Interested participants e-mailed the principal investigator and were sent a link to complete the screening survey (Appendix B). Participants who met inclusion criteria on the screening survey were sent a link to the Redcap online survey (Appendix C). Participants were also asked if they would be interested in participating in further studies. All of the enrolled participants were interested in participating in future studies and therefore were sent an invitation to participate in the qualitative interview.

An estimated 115 participants were planned to be recruited for this study based on the G power analysis performed prior to the initiation of the study. From April, 2016 to April, 2018 only 7 participants had been enrolled in the study. Sampling veteran caregivers is difficult because there is no accurate way to identify caregivers, they are spread out all over the country, and there is no official registry of caregivers that could be used to identify them. Barriers to recruitment included not having personal contact with participants or access to a caregiver database. An administrative principal investigator from the West Los Angeles Veteran Administration was not available and therefore recruitment could not be done through the VA as originally planned. The concern about the small sample size and the barriers encountered were discussed with the dissertation committee. The chair and members of the committee agreed to expand the inclusion criteria and change the design of the study. Inclusion criteria was expanded to include veterans with post traumatic stress syndrome (PTSD) utilizing a descriptive, exploratory mixed method convergent design with merged integrated results. An invitation to complete the screening survey was sent to 44 interested individuals with fifteen surveys not being returned and 3 women not meeting the inclusion criteria. Invitations to complete the quantitative survey was sent to twenty-six individuals. A total of twenty (N=20) completed the survey and were sent invitations to participate in the qualitative interview. From the twenty enrolled participants, a total of 7 (N=7) completed the qualitative interview. (Figure 5.1). Data from the qualitative interviews will be presented later in the chapter.

Figure 5.1: Study Recruitment



Descriptive Results

Specific Aim 1

The goal of the first specific aim was to describe the severity of emotional burden and practical burden in the female caregivers of veterans with invisible wounds of war. Caregiver demographics are displayed in Table 5.1. The mean age for caregivers was 39.3 (± 8.7) with the majority of caregivers being Caucasian (75%) and the wives of veterans (95%). Only one respondent was the mother of the veteran. Half of the caregivers were employed either full time or part time and the other half were either homemakers, retired, or disable. One homemaker was a part-time student and one caregiver worked both full time and was a full-time student.

Participants were well educated, with most caregivers (80%) having at least a college degree. Only three caregivers had no regular source for healthcare as the majority of participants had health insurance (90%).

Table 5.1 Caregiver Demographics (N=20)

Characteristics	Value
Age, years (mean ± SD)	39.3 (8.7) years
Age, n (%)	
Younger than 30 years	1(5)
30-40 years	11(55)
41-50 years	4 (20)
51-57 years	3 (15)
Missing (n)	1 (5)
Ethnicity, n (%)	
Hispanic	1 (5)
Non-Hispanic	19 (95)
Race, n (%)	
Caucasian	15 (75)
African-American	2 (10)
Identified more than 1 race	2 (10)
Other	1 (5)
Relationship to Veteran, n (%)	
Wife	19 (95)
Mother	1(5)
Work Status, % (n)	
Employed Full time or Part-time	50 (10)
Housewife	30 (6)
Retired/Disabled	20 (4)
Highest year of Education, n (%)	
High School	4 (20)
College/Technical School	14 (70)
Graduate School	2 (10)
Income, n (%)	
Comfortable – more than enough to make ends meet	5 (25)
Have enough to make ends meet	10 (50)
Do not have enough to make ends meet	5 (25)
Regular Source of Healthcare, % (n)	
Yes	85 (17)
No	15 (3)
Insurance, % (n)	
Private	50 (10)
Government (Medicare/Medicaid/VA)	40 (8)
None	10 (2)
Length of Caregiving, n (%)	
4-6 years	7 (35)
7 years or more	13 (65)

Characteristics	Value
Caregiving hours per week, n (%)	
5-19 hours	2 (10)
20-39 hours	7 (35)
40-79 hours	2 (10)
80 hours or more	9 (45)
Length of time since veteran discharged from service, n (%)	
2-3 years	2 (10)
4-6 years	10 (50)
7 years or more	8 (40)
Veteran Brain Injury, n (%)	
TBI only	7 (35)
PTSD only	3 (15)
Both	10 (50)

The majority of the caregivers had cared for the veteran for more than seven years with a mean of 7.6 years and a range of 4-14 years. Over half (55%) of the participants spent more than 40 hours per week caring for the veteran. Half of the veterans reported having both TBI and PTSD with the majority (60%) discharged from military service for less than six years.

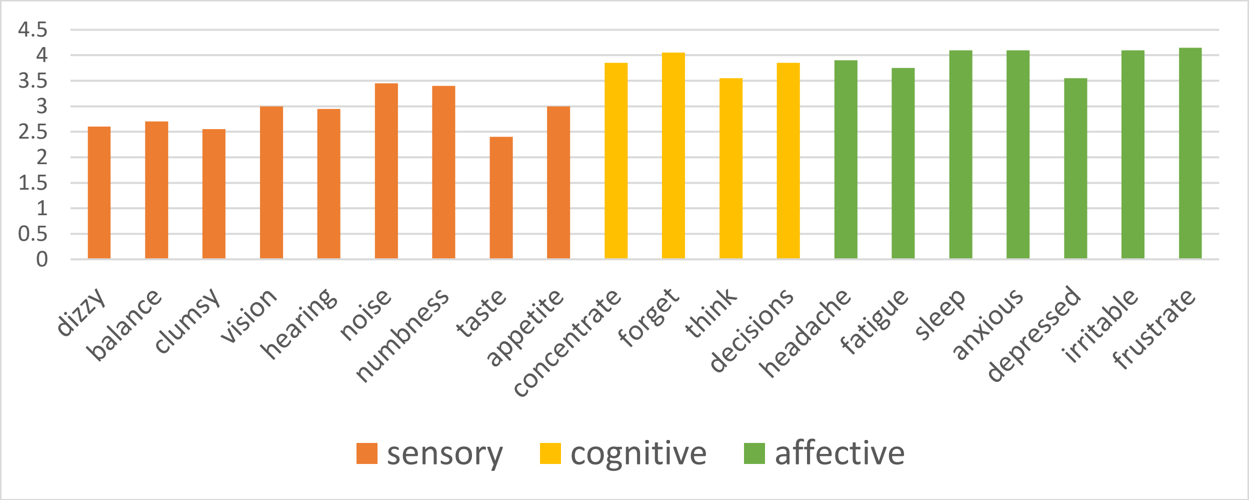
The Neurobehavioral Symptom Inventory (NSI) was used to measure symptoms in the veteran as reported by the caregiver. Itemized scores are presented in Table 5.2. In this study the NSI reliability was excellent, with Cronbach's alpha at .900. Figure 5.2 displays a chart of the veterans' neurobehavioral symptoms severity scores.

Table 5.2 Neurobehavioral Symptom Inventory (NSI) Itemized Scores (N=20)

NSI item	Mean (SD)	Percent rated severe or very severe ($\geq$ 4)
Poor frustration	4.15 (1.1)	70
Irritability	4.10 (.97)	70
Feeling Anxious	4.10 (.91)	75
Difficulty Falling asleep	4.10 (1.2)	70
Forgetfulness, can't remember things	4.05 (.89)	85
Headache	3.90 (1.2)	50
Poor Concentration	3.85 (1.2)	70
Difficulty making decisions	3.85 (1.3)	70
Fatigue, loss of energy, getting tired easily	3.75 (1.3)	65
Feeling depressed or sad	3.55 (1.3)	65

NSI item	Mean (SD)	Percent rated severe or very severe (≥ 4)
Slowed thinking, difficulty getting organized, can't finish things	3.55 (1.3)	60
Sensitivity to noise	3.45 (1.3)	55
Numbness or tingling on parts of body	3.40 (1.6)	60
Sensitive to light	3.35 (1.4)	45
Loss of appetite or increased appetite	3.0 (1.3)	45
Vision problems, blurring, trouble seeing	3.0 (1.0)	25
Hearing difficulty	2.95 (1.4)	40
Loss of balance	2.70 (1.3)	30
Feeling dizzy	2.60 (1.2)	25
Poor coordination, clumsy	2.55 (1.2)	15
Nausea	2.40 (1.4)	25
Change in taste or smell	2.40 (1.1)	20
1=None; 2=Mild; 3=Moderate; 4=Severe; 5= Very severe		

Figure 5.2 Veteran Neurobehavioral Symptoms Severity Scores

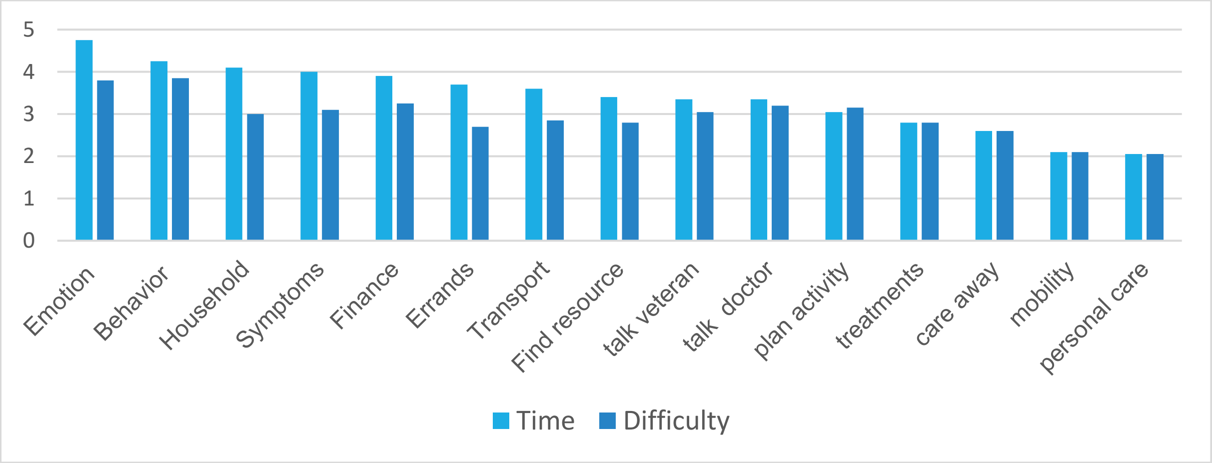


Practical burden was measured utilizing the Oberst Caregiver Burden Scale. In this study, reliability was excellent, Cronbach's alpha at .931. Itemized scores are presented in Table 5.3. Figure 5.3 displays a chart displaying the time spent and difficulty of performing each caregiving task.

Table 5.3 Oberst Caregiving Burden Scale (N=20)

Caregiving Task	Time Mean (SD)	Percentage large or great amount of time ≥ 4	Difficulty Mean (SD)	Percentage very or extremely difficult ≥ 4
Emotional Support	4.75 (.55)	95	3.80 (1.1)	55
Managing Behavior Problems	4.25 (.91)	80	3.85 (1.0)	60
Household tasks	4.10 (.97)	70	3.00 (1.2)	25
Monitoring Symptoms	4.00 (1.4)	65	3.10 (1.2)	40
Finances	3.90 (1.2)	50	3.25 (1.5)	50
Errands	3.70 (1.1)	55	2.70 (1.3)	25
Transportation	3.60 (1.2)	60	2.85 (1.2)	25
Finding resources	3.40 (1.4)	35	2.80 (1.2)	20
Communication with patient	3.35 (1.3)	55	3.05 (1.5)	40
Communicate with healthcare professionals	3.35 (1.2)	35	3.20 (1.4)	35
Planning activities	3.05 (1.1)	25	3.15 (1.3)	40
Treatments	2.80 (1.0)	30	2.05 (1.3)	20
Veteran care while away	2.60 (1.4)	25	3.2 (1.7)	50
Mobility	2.10 (1.2)	10	2.10 (1.5)	25
Personal care	2.05 (1.3)	20	2.30 (1.3)	15
Time = 1=none; 2= small amount; 3= moderate amount; 4= large amount; 5= great amount Difficulty = 1= not difficult; 2= slightly difficult; 3= moderately difficult; 4= very difficult; 5= extremely difficult				

Figure 5.3 Oberst Caregiving Tasks



Emotional Burden was measured utilizing the Involvement Evaluation Questionnaire (IEQ). As the participants were completing the survey anonymously, the IEQ was modified to remove questions regarding veteran drug or alcohol use, or dangerous acts committed by the veteran at the request of the UCLA Institutional Review Board. In this study, reliability was excellent, Cronbach's alpha at .892. Table 5.4 presents the Subscales and Total Scores for the IEQ. Caregivers reported spending a great amount of time worrying about the veteran (60%) and needing to supervise the veteran (55%).

Table 5.4 Involvement Evaluation Questionnaire Scores (N=20)

Scale	***n* items**	**Mean (SD)**	**Range**	**Percent rated as Often or Almost Always**
Tension	7	25.5 (6.5)	15-35	40
Supervision	2	7.7 (2.4)	3-10	55
Worrying	5	24.3 (4.9)	13-30	60
Urging	8	28.7 (8.7)	13-39	40
Sum Score[1]	20	74.6 (17.1)	42-99	
[1] Two items are used in more than one scale. The total score therefore differs from sum of the subscales.				

Anxiety was measured using the Generalized Anxiety Disorder Screener (GAD-7) and in this study, reliability was excellent, Cronbach's alpha at .925. Many caregivers (55%) reported anxiety that would be classified as needing further evaluation.

Depression was measured using the Patient Health Questionnaire (PHQ-8) and in this study, reliability was excellent, Cronbach's alpha at .872. A score of 10 or greater is considered major depression, 20 or more severe major depression. Participants reported depressive symptoms that indicated risk for major depression (60%).

The Perceived Stress Scale (PSS) was designed to measure the degree to which respondents found their lives uncontrollable, unpredictable, and overloaded. In this study, reliability for the PSS was excellent, Cronbach's alpha at .905. Scores are classified as mild stress (0-18), moderate stress (18-36), or very stressed (> 36). Most caregivers reported moderate amounts of stress (60%) or very stressed (35%) with only one caregiver (5%) reporting mild stress. Table 5.5 presents the mean scores for the GAD-7; PHQ-8; and the PSS.

Table 5.5 GAD-7; PHQ-8; Perceived Stress Scale (PSS) Scores (N=20)

Instrument	Mean (SD)	Range
GAD-7	11.90 (5.9)	3-21
PHQ-8	11.75 (6.4)	2-24
PSS	33.25 (9.7)	13-49

The Medical Outcome Study Social Support Survey (MOS-SSS) measures social support including four subscales: emotional/informational support, tangible support, affectionate support, and positive social interaction. In this study, reliability was excellent, Cronbach alpha at .958. Caregivers reported having support a little amount of time or no amount of time in the area of tangible support (60%) and positive social interaction (45%). Table 5.6 displays the MOS-SSS scores.

Table 5.6 Medical Outcome Study-Social Support (MOS-SS) Scores (N=20)

Subscale	Mean (SD)	Range
Emotional/Informational Support	2.88 (1.3)	1-5
Tangible Support	2.55 (1.3)	1-5
Affectionate Support	3.18 (1.4)	1-5
Positive Social Interaction	2.66 (1.3)	1-5
Total	52.90 (20.1)	19-90
1= None of the time; 2= A little of the time; 3= Some of the time; 4=Most; of the time; 5=All of the time		

Cardiovascular health was measured using the American Heart Association Life Simple 7 (AHA-LSS). As over half (55%) of participants did not know their physiological parameters (blood pressure, cholesterol level, and fasting blood sugar), the Life Simple 7 was simplified to include only four components including smoking, body mass index (BMI), diet, and exercise. Life Simple 7 scores are rated as poor, intermediate, or ideal and scoring for the four items used in this study are described in Table 5.7.

Table 5.7 Ideal, Intermediate, and Poor Levels of Life’s Simple 7 Components

Component	Ideal (2 points)	Intermediate (1 point)	Poor (0 points)
Body Mass index (BMI)	< 25 kg/m^2	25 to 29.9 kg/m^2	≥ 30 kg/m^2
Healthy Diet Scores*	4-5 components	2-3 components	0 to 1 component
Physical Activity	≥ 4 bouts per week of intense physical activity sufficient to work up a sweat	1 to 3 bouts per week of intense physical activity sufficient to work up a sweat	No intense physical activity to work up a sweat
Smoking	Never or former > 1 year	Former ≤ 1 year	Current
*Healthy diet score is composed of 5 components – 4 to 5 servings of fruits and vegetables, adequate servings of fiber and fish, and low salt and sugar in diet			

Caregivers demonstrated ideal cardiovascular health in that they were non-smokers (90%) or engaged in moderate intensity exercise at least four times per week (45%). Table 5.8 displays the Simplified Life Simple 7 Scores. Caregivers met the recommended levels of dietary fiber, sugar, and salt but did not have recommended amounts fish in their diet. Fruit and vegetable intake levels were low with caregivers averaging 3 servings per day. The mean score for Body Mass Index was 30.3 kg/m^2 (± 8.7, range 19.2-51.8) which would be classified as poor.

Table 5.8 Simplified Life Simple Seven Scores (N=20)

Component	Mean (SD)	Range
Body Mass Index (BMI)	.8 (.83)	0-2
Healthy Diet Scores	1.05 (.67)	0-2
Physical Activity	1.30 (.73)	0-2
Smoking	1.80 (.62)	0-2
Total	4.95 (1.6)	2-8
0 = Poor; 1 = Intermediate; 2= Ideal		

Summary

Caregivers reported spending the greatest amount of time providing emotional support for the veteran and managing behavioral problems. The two most frequently reported neurobehavioral symptoms in the veteran were forgetfulness and anxiousness. Caregivers reported being moderately to severely stressed by the numerous caregiving tasks that needed to be performed. Participants did receive emotional, affective, and informational social support but tangible support (support if the caregiver became ill) was lacking. Emotional burden included worrying about the veteran and needing to supervise the veteran. Many caregivers demonstrated anxiety that would be classified as needing further evaluation and depressive symptoms that indicated risk for major depression. Higher scores for depressive symptoms were correlated with poorer cardiovascular health.

Specific Aim 2

The goal of the second specific aim was to evaluate the relationship of caregiver burden to type of neurobehavioral symptoms (somatic, affective, or cognitive) in veterans. Veterans neurobehavioral symptoms were positively correlated with caregiver physical burden (r =.782, p <.001) including all of the NSI subscales: affective (r=.770, p <.001), cognitive (r=.634, p=.003) and sensory (r=.737, p<.001). Table 5.9 describes the relationship between neurobehavioral symptoms and physical burden including time and difficulty.

Table 5.9 Relationship Between Veteran Neurobehavioral Symptoms and Caregiver Practical Burden

	Pearson Correlation	Significance (2-tailed)
Symptoms total/Practical burden	.782	>.001**
Affective symptoms/Practical burden	.770	>.001**
Cognitive symptoms/Practical burden	.634	.003**
Sensory symptoms/Practical burden	.737	>.001**
Symptoms total/time caregiver spent on tasks	.760	>.001**
Symptoms total/difficulty of caregiving tasks	.782	.001**

Veterans' neurobehavioral symptoms were positively correlated with emotional burden (r=.807, p <.001) including all of the NSI subscales: affective (r=.819, p >.001), cognitive (r=.623, p .003) and sensory (r=.760, p >.001). Table 5.10 displays the relationship between neurobehavioral symptoms and emotional burden.

Table 5.10 Relationship Between Veteran's Neurobehavioral Symptoms and Caregiver Emotional Burden

	Pearson Correlation	Significance (2-tailed)
Symptoms total/Emotional Burden	.807	>.001**
Affective symptoms/Emotional Burden	.819	>.001**
Cognitive symptoms/Emotional Burden	.623	.003**
Sensory symptoms/Emotional Burden	.760	>.001**

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

Specific Aim 3

The goal of the third specific aim was to explore the relationship of psychobehavioral caregiver variables to cardiovascular health. Overall, lower summed scores for smoking, BMI, diet and exercise items of the AHA-LSS indicated poorer heart health and were correlated with higher scores for depressive symptoms (r= -.648, p=.002) and perceived stress (r= -.534, p=.015). Higher levels of caregiver practical burden including more time spent on tasks and more difficulty performing tasks and higher levels of emotional burden, and higher levels of anxiety were correlated with poorer heart health scores but these relationships did not reach the level of significance. Increase levels of caregiver support was correlated to better heart health but this association did not reach the level of significance. Table 5.11 displays the relationships between cardiovascular health and caregiver psychobehavioral variables.

Table 5.11 Relationship Between Caregiver Heart Health and Caregiver Psychobehavioral Variables

	Pearson Correlation	**Significance (2-tailed)**
Heart Health/ Caregiver Social Support	.200	.398
Heart Health/Time spent caregiving tasks	-.205	.387
Heart Health/Difficulty of caregiving tasks	-.268	.253
Heart Health/Practical Burden	-.265	.258
Heart Health/Emotional Burden	-.351	.129
Heart Health/Perceived Stress	**-.534**	**.015***
Heart Health/Depression	**-.646**	**.002****
Heart Health/Anxiety	-.390	.089

*Correlation is significant at the 0.05 level (2-tailed)
**Correlation is significant at the 0.01 level (2-tailed)

Summary

Results of the quantitative study demonstrate that caregivers perform a variety of caregiving task including monitoring cognitive and affective symptoms in the veteran and providing emotional support. Affective symptoms were not more highly correlated with caregiver burden as hypothesized. Both perceived stress and depression were correlated with poorer cardiovascular health. In the next section, results from the qualitative interviews will give a more complete picture of caring for a veteran with invisible wounds of war by allowing individual caregivers to describe their emotional response to caregiving and daily stressors they encounter.

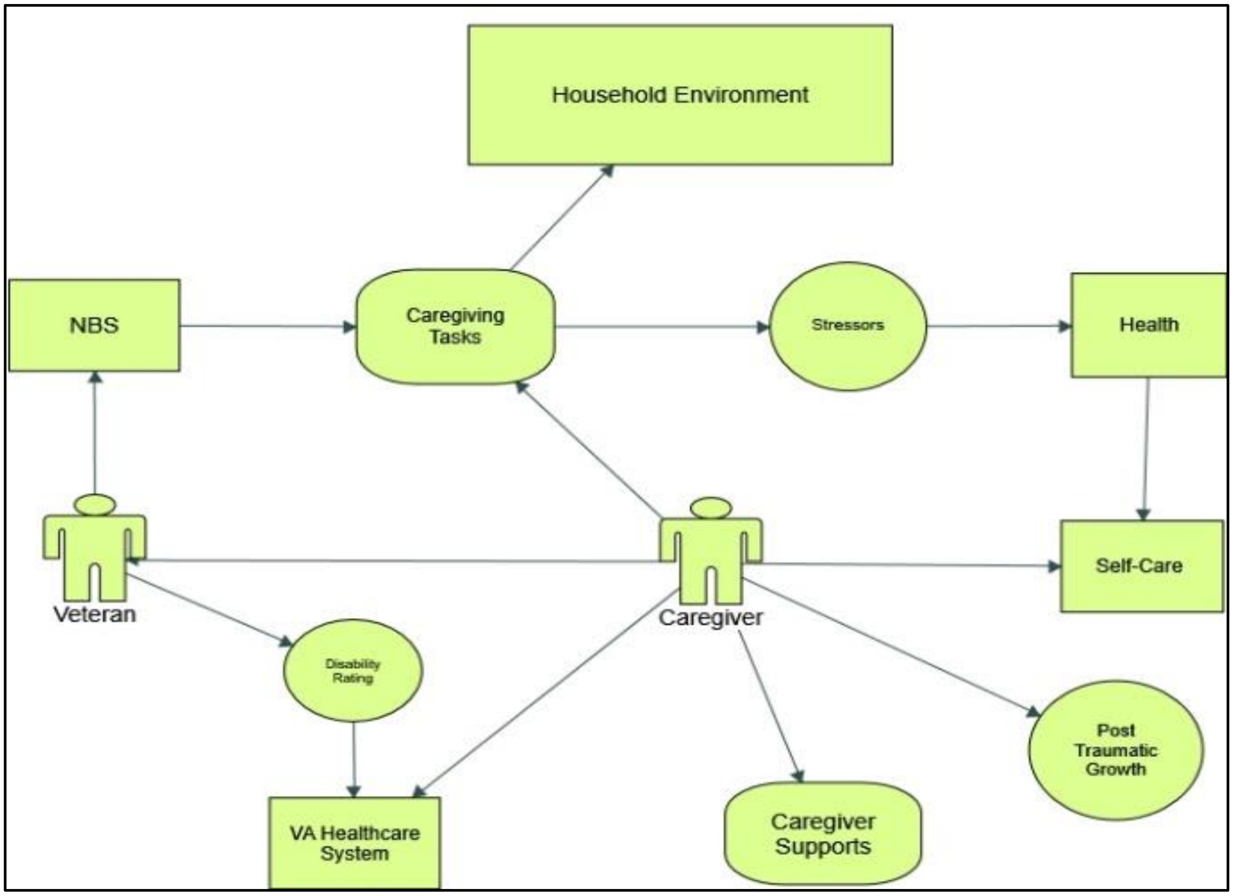
Qualitative Analysis Results

The goal of the qualitative analysis was to describe the experiences of caring for the veteran in the home setting and the effects on the health of the caregiver. A term frequently used by the participants was “same story, different faces”. Seven themes emerged from the analysis: managing neurobehavioral symptoms, managing the veteran in the home setting, accessing and navigating the healthcare system, caregiver self-care, caregiver supports, posttraumatic growth, and motivation.

Analysis Procedure

All interviews were audio recorded and transcribed. Transcripts were summarized utilizing a template of key domains (Appendix D). The data was coded for concepts and sorted using NVivo 12 Plus software (QSR International). The software is a Windows-based program in which verbatim transcripts were pasted into individual participant files. Interviews were read, coded and analyzed for emergent themes guided by the following concept map:

Figure 5.4 Concept Map



The following themes emerged:

1. Neurobehavioral Symptoms: Managing the Unpredictable
2. Home Environment: Home as the Safe Place
3. VA Healthcare System: Fighting to Navigate a Complex System
4. Self-Care: Finding Time to Care for Self
5. Caregiver Supports: Caregiver Peers: Creating a New Community
6. Post Traumatic Growth: Learning to Become the PTSD Expert
7. Motivation: Sacrificial, Unconditional Love

Sample

All of the women who completed the online survey were invited to participate in the qualitative interview. Seven (N=7) of the women consented to be interviewed with six being interviewed by phone and one in person. Ages of the participants ranged from 30 to 54, there were 6 veteran spouses and one veteran mother, 3 were homemakers, 3 were employed, and one was disabled. Length of time caring veteran ranged from 5 years to 14 years. The following table describes the demographics of each participant utilizing pseudonyms for name to protect their identity.

Table 5.12. Participant Demographics for Qualitative Analysis

Name	Age	Relationship to Veteran	Employment Status	Veteran Military Discharge Date
Mary	38	Wife	Housewife	2004
Trish	37	Wife	Housewife	2006
Ann	31	Wife	Housewife	2006
Joy	30	Wife	Full-time	2011
Meg	54	Mother	Disabled	2012
Lynn	52	Wife	Part-time	2013
Sarah	48	Wife	Full time	2013

Results

Theme 1:

Neurobehavioral Symptoms: Managing the Unpredictable: “*Walking on Eggshells”*

All of the caregivers reported dealing with affective symptoms in the veteran on a daily basis. These symptoms included difficulties with sleep, feeling anxious or hypervigilant, feeling depressed or suicidal, and irritability and poor frustration tolerance.

Veteran Affective Symptoms

A. Sleep Issues:

Ann: “My morning starts with my husband uh he doesn’t sleep very well at night due to numerous reasons um night terrors um are a big thing. But he is also very hypervigilant. He feels like when he goes to sleep that something bad is going to happen on his property or around the house. Um stuff like that. So, he wakes up very late in the morning. I end up having to wake him, we sleep in separate rooms. My kids and I all sleep in the master bedroom together but he sleeps on the couch or whatever.

Joy: “A normal day usually starts with me um care recipient wakes up very, very early so by the time I get up he has been up for at least 4 hours. So, I’ll check-in with him and see how he is doing.”

Meg: “He’s the opposite of me, he has insomnia. He sleeps through the day and then is up at night. He hasn’t slept yet, he’s still up.”

B. Anxiety and Hypervigilance:

Mary: “He has anxiety. It has been an argument in our household that when I got diagnosed with anxiety about 2 years ago, I didn’t know it was an anxiety attack. I thought I was having a full-on heart attack um then I ended up in the ER and they said what you are experiencing right now is an anxiety attack. And I at that point did not know what that was - I never felt that way. And you know he was kind of, he was almost kind of offended that I was suffering from that right now because the way he explained it to me, he says what you are feeling right now, I feel every day. It never goes away.”

Ann: “He really does not get out much, he does not like crowds. I try to keep him you know busy, be occupied cause if he just sits there you know things can get kind of um bad, I guess where he just dwells on things that have happened or stuff. Um a normal like everyday occurrence is he has you know he’s very hypervigilant and if an unmarked car comes like yesterday there was and I am pretty sure he was here for the neighbors there’s a teenage boy and a person kind of like they often park in front of our house, he’s standing there watching you know thinking like is that a potential threat to him and his family. So, he’ll like take down license plates. Yesterday he took down the license plate, he took pictures with his phone you know. Um to make sure he has a good description of who was driving the car.”

Lynn: “There was a point where I could tell, we sat down and the seats were kind of close together - and there was a lot of people - and I could kind of tell he was getting anxious. he got about half way through and started kind of feeling anxious like ok that’s it, I got to go. I think he was getting anxious too looking around at all the people and knowing that when it’s over, we have to try to like get our way through the crowd. And he didn’t like that.”

C. Depression and Suicide

Mary: “Ulcerative colitis. Yes, it has progressed, uhm a lot of blood in his stool. His depression is on an all-time high once again. Ryan, he has suicidal tendencies, he has tried to commit suicide over 5 times. He deals from survivor’s remorse. He doesn’t feel like he should be back. That is another trauma that has come into the mix. He’s dealing with all that right now too. So then of course you are opening another wound and for me it is like um is this going to put you in a place again that you want to end your life because that’s kind of Ryan’s pattern when it gets too much for him, he wants to take his life.”

Sarah: “Almost a year ago um August 9 a year ago he had an um suicide attempt and 7 weeks ago um he was getting to the point that he was suicidal again.”

Trish: When we moved here, he tried to kill himself on the way here. That was in 2010 when we’re on a road in the middle of California. I didn’t understand PTSD or TBI. I just knew he got upset and he was trying to stab himself. He has meds for anti-depressant now”.

D. Irritability and Anger:

Joy: “I try to keep in touch with him, to make sure he’s on the even keel. And sometimes when I get home it just hits the fan for no apparent reason. I don’t even pass the threshold and there’s some issue where he’ll start in on me. Like there was one situation where I came in with groceries, a few bags of you know groceries and things and he would be “Oh we didn’t talk about this, you like never um you should have told me you were going to this and he’ll grab the bags out of my hands and throw them against the wall or stuff them on the floor or throw things through (sighs) One time I brought home take-out um he didn’t like it so he took it and threw it all through our window, our kitchen window like he broke our kitchen window with plates, like he made a huge friggin mess everywhere.”

Lynn: “He’ll get agitated or um short tempered or um he has no filter so he’ll just say if someone’s in his way or if someone’s bothering him, not bothering him but you know like where he feels threatened at all. He just doesn’t have a filter so he’ll just say what he needs to say in public and sometimes it’s not appropriate.”

Mary: “I would have to say that 2 weeks ago was a day that was unbearable. Ryan gets really verbal, verbally abusive uh he uh you know anything and everything you do will irritate him.”

Sarah: “He would get irritated or he would have a bad day at the treatment facility. I could ask one thing, say something wrong, look the wrong way, say it in a wrong tone and then um everything would hit the fan. Um he would be extremely angry. Um he has angry outbursts.”

Trish: “He’s a little more grumpier until I give him his meds. He gets in these moods where he might not want to go to work (laughs, giggles) over something silly like the animal kept him up or his whatever is going on. He got up, he was not in a good mood and I left because he was not in a good mood. I felt like I was on eggshells in the morning.

Ann: “He’s just upset or mad about something or he’s having some sort of episode or it’s some sort of anniversary or somebody’s birthday or he had therapy. You know what I mean there’s just like so many things that but I mean he spends like every day just pissed off for no reason.”

Cognitive Symptoms

The most frequent cognitive symptom that veterans exhibited was forgetfulness. Being unable to concentrate or pay attention, veterans had difficulty completing tasks and, in some cases, rendering them unable to care for children in the home.

Trish: “I would remind him “Hey we got to pick up your son from tutoring, you know you got to there is all of these events happening and then he’ll forget. And I’ll text him to remind him, that is when I it gets stressful. It is when I am somewhere else and he’s trying to take care of the household. And he will go do something and then he will forget or he will not follow through. Or he is calling me “Was I supposed to get my son today?”

Mary: “I have an issue with him being forgetful. Yesterday I had timeframes that I needed to remind him to you know take his uhh laxatives and then that drink that he has to do, so I had to be sure that he was on that. He doesn’t know how to problem solve.”

Sensory Symptoms

Veterans can be irritated by noise. This is especially difficult in households where there are young children.

Lynn: "They invited us over for dinner which at first is nice because it helps him relax to be around the kids. But about after 20 minutes (laughs) he's had enough, there's a lot of noise. At work he has his in office so he can close his door and get quiet time."

Theme 2:

Home as The Safe Place: "*I Spend My Day Making Sure He Feels Safe"*

Household Environment

Besides the routine household maintenance chores of cooking, cleaning, laundry, and shopping, participants also had caregiving tasks including health maintenance, emotional support, obtaining medical care and advocating for the veteran. Household environments can range from calm and organized to chaotic and disruptive. The nature of the household environment is affected by the severity of neurobehavioral symptoms in the veteran and the presence of young children. The older women tend to have calm and organized households with the one veteran who is working full time being the most stable. The younger caregivers have more difficulty in managing neurobehavioral symptoms in veterans.

Lynn is a 52-year-old homemaker who lives with her husband. She works part-time home-schooling her sister's children. Her husband works full-time at the Veterans Administration (VA) as a National Service Advocate helping other veterans with obtaining their disability ratings. Her children are grown and the youngest just graduated from college. Although her grown children no longer live at home her sister and mother live around the corner. Working for her sister gives her more flexibility to care for her husband**:**

"He does work and I do work part-time for my sister but not in the summer. Summers are a little bit more relaxed because I'm home. My stress level isn't as much as a lot of people that are dealing with – we're dealing with the same issues, but we are not dealing with the kids in the mix. I'm constantly making sure that he is taking his medicines, making sure he doesn't forget his appointments. One of the reasons I don't work a real job. I mean it's a real job but I work for my sister so if he has a doctor's appointment, I don't - I'm not coming over. You're gonna have to figure it out because I'm going with him to his doctor's appointment. I can't do that with a regular job."

Meg is a 54 -year-old disabled mother who lives with her son. Both are considered homebound. The caregiving tasks she performs for her son are in addition to attending to her own health issues. Primary caregiving responsibilities include medication management and reminding her son of appointments. She would like to move to a retirement center but is concerned that her son would be unable to manage the household on his own:

"His health has kind of been deteriorating since about uh you know now, he has MS. They gave him a new medicine yesterday and I put it in the pill sorter. I'm starting to go ahead and put his medicines in the pill sorter. Um he was having the adverse reactions already of flushing which I didn't even know what that meant. We called and talked to the VA today about the medication. I put in a bunch of applications to move into a senior facility but I don't know if he can live on his own. I don't know if I am going to have the energy to keep an apartment for myself and supervise. You know we have a house here you know sell the house to him and then supervise him with taking care of it because him taking care of it is not going to happen. It's not happening now with me here I mean you know. I do all the overhead all the bills and everything you know. And somebody was saying that if you step out of the picture, he'll have to but I don't know he just never feels good. The thing is that I got my own chronic illness on top. Sometimes he and I will look at each other and say who's taking care of who here."

Sarah is a 48-year-old wife. The household is currently in transition as the veteran was just discharged from an inpatient PTSD program and she is currently on family medical leave and in the process of retiring from the police department for her own health issues. She has a 7-year old daughter at home and an older an older daughter. Her husband's hospitalization has taken a toll on the whole family**:**

"For the most part I feel that I hold it all together. But, especially in the past year since his um attempt um it has been, it's, it's probably been the hardest year. Before October when they changed my hours, we were splitting that either I would take her to school and he would pick her up or vice versa. Uh he, he does a lot with our daughter when he's healthy. But, especially in the past year since his um attempt um it has been, it's, it's probably been the hardest year. We try to share the load around the house. Um but you know the past 7 weeks has been rough on all of us. I have older kids as well, um a 21-year-old that actually watches my 7-year-old. So, she had to pick up a lot of flak since he was gone. You know it was rough on the whole family – and him. We did not well I can tell ya for 2 ½ months after his attempt, I hardly left the house. I, I didn't work at all. I stayed home."

Mary is a 38-year-old homemaker with 3 boys ages 15, 11, and 5. She was trained as a medical-surgical RN in Germany, but has not practiced nursing since moving to the United States. Her husband was discharged from the service in 2004 and therefore, Mary has the most experience of dealing with invisible wounds in the home setting:

"Everything is structured in our household which umm is kind of easy for me because my background – I gave up my career doing what I am doing for him, I am an RN – I am pretty much structured. Ryan gets up around 6:45 or 7:00 ish. I make sure he takes medication because I have an issue with him being forgetful. Medication reminders throughout the day with him because he takes meds on different hours of the day. The kids get home at different times… when they come home of course homework time, I uh that is my area, I kind of deal with that and then it is close to dinner time. We eat dinner as a family. everyone kind of winds down and we usually go to bed by 9:30 well the adults in the household from 9:30-10:00. Well, once again I need to make sure he takes his medications, uhm he is a CPAP patient, I have to make sure he has his CPAP on that night and then we just turn in for the night. We typically go 24/7 - I always say that people that are dealing this having this lifestyle, it has become our norm."

Trish is a 37-year-old mother of 2 boys ages 5 and 7. Her husband has a part-time job with flexible hours. They live in a house that was donated to them by a veteran organization. They do not have family nearby for support:

"His job is pretty laid back, where they're like come in when you can. You can leave early. If he has a bad day he'll just say "I didn't sleep, I am not going in". And it will kind of affect the whole house because maybe I got a babysitter that day so I could go exercise and my whole plans are changed when he jumps from, I am going to work, I am not going to work. A normal day just calm in the morning, got the kids up ready for school. It's about how the kids not throwing tantrums either. Uh he gets up ready for work, he seems excited, he takes a shower by no pain, no back pain always is a good day. Uh and he goes to work. And then I get the kids to school and then I pick them up and uh. He comes home. I make a dinner. Uh he's interactive with the kids. That's always a good day too and not isolating himself in the room."

Ann is a 31-year-old housewife who home schools her two boys ages 7 and 3. He husband is disabled and leaves the house only for VA appointments. Her parents live in the neighborhood and as her mother is retired, she helps with the children and as needed by the caregiver**:**

"I normally have to wake him up because he has medications that have to be taken before a certain time. Um so I end up having to wake him up, we sleep in separate rooms. Um so I wake him up and administer all medications throughout the day. Mostly it is just in the morning and night and obviously emergency situations. He has specific pills that he can take which I give, I am in charge of making sure he takes them. If I don't give them to him, he won't take them and if I don't keep them locked or put away, he takes too many of them or he tries to. And so, I do that – it's a daily thing. So that's how my mornings normally start. That's on top of taking care of my two little guys. I have a 7-year-old and a 3-year-old, little boys. he doesn't do crowds. So, he's pretty much in the house all day. I try to keep him you know busy, be occupied cause if he just sits there you know things can get kind of um bad, I guess where he just dwells on things that have happened. I spend my day making sure that he feels safe and it's like walking on a lot of egg shells because everything is a fight. Like if I don't do something correctly, I mean you know it's just a fight. And you know I try to keep that at a minimum because we do have children here. Um pretty much that is my day unless he's got an appointment to go to and we you know have to go to that or whatever. Otherwise I just make sure he is taking care of himself. And make sure that he is ok that he's showering because I obviously have to remind him to do that. Um stuff like that – that's pretty much my day."

Joy is a 30-year-old college educated and works full-time as her husband is disabled. The military moved them to Washington State where they both have no family nearby. They would like to move closer to family but cannot do that until he receives his veteran's disability pension:

"Well a normal day usually starts with me um care recipient wakes up very, very early so by the time I get up he has been up for at least 4 hours. So, I'll check-in with him and see how he is doing. Um basically do a health and welfare check, see how he is doing, are there any issues any health stuff he needs help with. Um we'll try to have a meeting to set our days up, to see if there is anything that we need to talk about or any health things he needs to talk about or address with me that we need to partner up on. We'll talk about that and then um I go for I have to work outside the home so I will get ready and leave for work and all that. And then I'll probably check in on him maybe 5 or 6 times a day while I'm gone to see how he's doing and all, I'll text him a like couple of times in the morning and on shift. When I get home, we'll you know normally I cook, I try to ask him to cook but it doesn't like happen, he always says "No, I don't want to cook" but he doesn't. And yep we do dinner and have our we try to have another morning meeting but sometimes depending on his symptoms that doesn't work. Basically, when I just get home, I try to see what on earth has gone on since I've been gone and take it from there. It's my (laughs) really short day, that's how my day goes."

Caregiving Tasks

Caregivers perform physical health maintenance tasks and provide emotional support for the veteran. They advocate for the veteran to obtain medical care and access veteran resources. As care is often fragmented, they function as a care coordinator across multiple departments and health care facilities.

A. Health Maintenance

Health maintenance tasks includes monitoring symptoms and watching for treatment side effects. Caregivers not only manage the behavioral problems of PTSD but also must assist the veteran with symptoms of pain or fatigue or identifying signs and symptoms of new conditions. Caregivers also encourage the veteran in healthy behaviors and lifestyle changes.

Mary: "He also suffers from ulcerative colitis. That is why is having his colonoscopy today, it has progressed, a lot of blood in his stool. We had some medication changes from the mental health aspect and then there has been a lot of tweaking of meds."

Trish:" He got hurt and one was from the blast of the hand grenade. It went to the spinal cavity. The doctor said if it went a centimeter over, he would not walk today. He's very lucky to walk even if walks like an old man I say. All he did was go to Boy Scouts with our son and he couldn't move. He was screaming in bed. I almost called 911. I got Tylenol in him, got his shoes on, and take him to the doctor. And this is where we are at – it's a cycle of "Well you're young, you don't need surgery. But then he can't live his life. They go more physically therapy, more physical therapy. More of this he's got degenerative discs, he's got bone spurs, stenosis. He's got the arthritis."

Lynn: "He's got a lot of neck and back pain and he has degen, I think it's called it degenerative disc disease and he has uh oh I can't remember what it is called with his neck. But um he was supposed to get some injections in his neck a couple of weeks ago and they cancelled it and reschedule it for uh like mid-August. Um so things like that, I mean I'm super scared about that. I don't want anything to do with your back and your neck. And I think it's just uh like cortisone."

Joy: "We both of us eat very healthy um for sure. That's helped a lot because he had a really bad diet when we first got together. We've been together for almost 10 years so it's been a work in progress but we definitely I would say our lifestyle overall is like a 7 out of 10 or 8 out of 10 as far as healthiness and all that so we're good on that. Things used to be really bad when we were sedentary and ate you know crappy food and weren't mindful of all that stuff. So, for sure it has gotten better since we made lifestyle changes."

B. Emotional Support

The most frequent task that caregivers perform is providing mental and emotional support for the veteran. They help the veteran cope with stressful situations, avoid triggers of anxiety, and thwart antisocial behavior. Caregivers often are the ones that identify PTSD triggers and triggers can include noise, smells, or crowds, anniversaries, or appear suddenly upon awakening or after a therapy session.

Mary: "We would go to a restaurant, or we would go to the movies or, and he will still do these things with me but I know, I say it is like we eat and we run after dinner because I see that with him, I just get him. I always have this joke I know exactly what kind of day it is going to be when he wakes up. Is it going to be a good day, is it going to be a bad day because we are just in sync with one another. And the thing with dinner, he will start scanning the room and I will say "You're ready to go" and even if I am not you know at least he sat and had a meal you know. So those are kind of the things you know that you built in these relationships."

Joy: "There's a really long list that I've been able to piece together through time. But what I've found the most common things that triggered it is um location, um smells, time of day, like certain sounds. Um all of these things will trigger it and it will to come out - out of nothing. Or even it can be as simple as if um I "sass back" at him or whatever. That's a trigger too.

Sometimes like the most stressful day I have would be when I was woken up to screaming and things flying and um yelling and basically, he's had like a slide, he's been woken up by a flashback and it woke me up because he was out in the living room like throwing things and having issues. So that's a really stressful day. And that happens like every so often maybe a couple of times in a month, maybe less. One to two times a month I would say that happens where something will wake him up and he won't know it until he completely not a participant in or private basically, in a conscious way. So, that really stresses me and sometimes when that happens, I won't be able to leave until I either get him medical treatment or he comes to from that.

Most of the time it involves EMS. What I'll do is just call 911 and tell them what the situation is and sometimes they'll send a cop, sometimes they'll send a firetruck or ambulance. It just depends on the situation. But it usually entails law enforcement. He won't um let me take him to the doctor if he is having an issue, there has to be like outside help to get to get him to go to the doctor."

Ann: "Like an anniversary being like um April 11 when, which happens to be my Mom's birthday but it's also like in 2003 when he lost like lost most of a number like all of his friends. Like a bunch of people just like died. I don't I only know that day hit like in his life. Like people died, one of his good friends died and he was injured. That where he got his TBI. You know and stuff like that can be a really bad day. Memorial weekend Memorial Day that makes for a really bad day. Um because it is Memorial Day you know. Um he normally chooses to just go and get drunk and I have to go find him and hopefully not pick him up out of jail.

I try to get my kids out of the house on days that I know like Memorial Day or April 11 which is my Mom's birthday. We usually normally go out with her anyways for a little bit. I'm with my kids though. You know I try to plan a barbecue. Or you know like this Memorial Day we went barbecuing anyways and get my kids out of the house. But like I know I can't leave all day so I try it's really hard for me so I try to go for an hour. I come back and check on him.

A bad day can be anytime he goes to therapy because he's doing, he does exposure therapy. And for whatever reason that makes him because they are touching on things specific events that makes him like really aggressive, really upset. So, then I have to deal with that afterword's."

Sarah: "June is a really hard month for him. He has um anniversary dates from combat and it is almost like a uh it's a reoccurring issue every year. Hopefully it won't be next year but it's been every year.

Trish: "He got up, he was not in a good mood and I left because he was not in a good mood. Ok kind a bad day, a normal day isn't always like that. Yeah but he was getting upset and I didn't want to him being upset around the children so I said "You know what, we will go to the park and we'll have fun" and give him some time to calm down. Come back, it's like a whole new person and he's calmer."

C. Being Present and Listening

Caregivers have found that their most important caregiving task is to be available and listen to the veteran while he works through the symptoms. Triggers of stress in the veteran can occur at any time; caregivers must be present to provide emotional support. Finding time to simply listen to veteran allows him the opportunity to think through the problem and develop his own strategies to manage his symptoms.

Mary: "We have learned that through counseling so marriage counseling must be doing something for us because he will come to me at times saying "I just want you to listen, I don't want you to say anything to me. I just want you to listen". And I do. You know I will sit here and I will listen. And there are times when he will say OK you know I am going to tell you something and I want your opinion or you know we have kind of learned to communicate better with one another."

Joy: "Like we can't just be a normal couple that does normal things. We have to talk through things a lot more than normal couples do. We have to communicate extremely openly and we just have to yeah, we just have to be totally blunt about everything. If he has an issue and then it's literally as soon as I can tell he's back then we'll have a talk like you need to not do this or you need to do this or. But he'll normally say "Oh the reason I do this is because I care about you or "I say yea or "I have this experience from the past and I just want to keep you safe from whatever so I'm sorry I'm so excitable and you know upset about these things but they happen for xyz reason and this is why I feel this way" and all this kind of stuff. So, we normally do talk about it afterwards, like immediately afterwards. Um so both of us are on the same page and we can grow from that."

Theme 3:

VA Healthcare System: Fighting to Navigate a Complex System: *"He Might be Back, but I am still at War, still Fighting"*

Advocate

Unique to caregivers of veterans with service-related injuries is learning to advocate for the veteran and navigate the complex Veteran's Administration (VA) Healthcare System. In order to qualify for care, the veteran must demonstrate that his injuries were related to their military service. Trying to obtain care for the veteran through the VA can be challenging and stressful for the caregiver as it may take years for the veteran to obtain their disability rating.

Mary: "Nobody was prepared for what we were getting into. We came here in '04 and started the process with the VA. I always say he might be back, but I am still fighting. In the beginning, uh when he was being diagnosed, it is none of your business what we talk about in the office. All you need to know is that I have PTSD. I mean he was very, he didn't want me in his business and what now and then he didn't want me to be in the doctor's office with him, I would have to sit outside. So, I really felt disconnected from the treatment. For me to do what I do I need to be connected, I need to know the doctor prescribing this medication and what is this medication for and you know what are the warning signs.

Ryan is 100% disabled, he got rated 3 years ago through the VA they found he was not able to hold a job with all of his stress and a year ago it became permanent. Now I am connected with all of his doctors, I can secure message. They will call me, we started him off on this - if you see anything so now, I am very connected and he has an excellent team that cares for him. Now I am a very strong advocate not only for my spouse but for other veterans. I have helped other veterans get the resources they need."

Lynn: "He went back to school online and it took him a long time but he finally got his bachelor's degree and that helped him get the job um at the VA. He's a veteran's advocate, he's called a national service officer. He gets such a high when a veteran comes in and he keeps getting turned down. Jim helps him with his paperwork and it comes back and he gets say 80% or 90% or even 50%. He gets such a high off of that knowing that he helped that veteran out of a place that he was in once. Because it took him over 2 years for the VA to get all of his disability paperwork done. About a year in they let us know, he still hadn't gotten his disability done and they let us know that they lost all of his paperwork. So, we had to start all over, we had to make copies of everything and start all over again. So, it took him over two years to get his disability. So, now he's in a position where he can make sure that doesn't happen to somebody else. And he loves it, it's so good for him."

Meg:" His injury occurred in 2010 a 375-helicopter blade hit him in the head and it was not until 2015 that an MRI and mild TBI diagnosis was done. I mentioned his poor memory and all the behaviors I'd been dealing with for 5 yrs and the VA took action. They just kind of discharged him to Mama and he's been living here and we together had to navigate the system. I didn't know that I was a caregiver until 2015 when I was so stressed out with all of the behaviors. Um you know from the brain injury and everything else, behavior, the aggression, everything um I called the caregiver hotline. I called them before but this time I called them they said if he lives with you then you're considered the caregiver. So, in 2015 is when I started going to appointments with him and things started happening. Um changes started happening.

Then he started advocating for himself. Um he got 20% benefits in '12 and then by 2016 he was getting 100% social security disability and then 70% VA benefits so that's kind of where we are now. He's been waiting 2 years for the Washington DC the appeal there. He's had 3 appeals, 2 in St Louis, uh Missouri and one now has been sitting on the judge's desk. That's two years for his mental health uh PTSD and then he got the MS which can expedite the case possibly. Now he has a lawyer so the lawyer, we got the paperwork yesterday from the VA and I mail I copied it all and I mailed it off right away to the lawyer's office. Um they have a special veteran's lawyer. So, yeah all of this stuff has just been STRESS."

Joy: "We got like stuck here dealing with VA and admin stuff. None of his stuff is rated. They refuse to accept that any of his stuff is service connected. Even though his team leader like has a sworn statement that says like "Oh we have *x* amount of combat missions that we got like blown up all these times", it says line by line what all his injuries are but yet the VA is still like "not service connected, not service connected". It's in appeals now.

The VA stuff was submitted in like 2012 at least. And I was like "Oh yeah eventually, when we first moved up here, so I thought oh yeah he'll easily get his 100%". Like it's just one person has to stamp it and all the stuff's in a packet, I'll get CHAMPVA and I can go to the doc and all this kind of stuff and it was supposed to work out really smoothly, easily and it just hasn't this whole time. We had a VSO advocate friend um who got a really awesome job offer and he moved. So, we don't have anyone. I need to find a new person, we don't have anyone helping on the appeal."

Obtaining and Coordinating Professional Care

Caregivers assist the veteran in disease management by attending physician appointments in order to understand the medical plan of care. Caregivers will also coordinate care between VA departments and VA facilities in different locations. When the VA is unable to meet the needs of veterans, caregivers will go outside the VA and obtain care in the civilian community.

Mary: "A lot of caregivers that I speak to are like "You go to every doctor's appointment. I am like isn't that what we are supposed to be doing?" He says it you know when I don't have you, I feel like I am missing a limb. I am trying to get him to the point where he like you don't have to have me there when you are doing labs, you don't have to have me there when you are just having an x-ray of some sort. I mean the important stuff yes, but you go to neurology I go too, the TBI clinic with him, the PTSD clinic with him, or his primary care.

I don't think they know the full scope on what we do at the VA. You know I tell them all the time., I am keeping him out of your hospital. I am keeping him out of your mental health facility. I am making sure he is on his meds. I'm making sure he is not going to be a lunatic running around the world shooting places up. I mean that's what we do."

Meg: "I had to call the doctor to get (sighs) results the he called me back and I was at my doctors and I was in stirrups at that point. You know he couldn't tell me the results because my son wasn't there. So, I rushed home so that he could tell us the results after 3 weeks of waiting after the spinal tap and this doctor only comes in for 3 hours to the VA, he works at the medical school. And then I call him there and then he put all that in the record, in my sons record. "His Mom is calling here and my other place of work and all that other stuff." You know I don't know I don't always feel the support."

Joy: "I do talk him into going into the actual hospital every year, since his primary care makes him do blood work and stuff so. That's my excuse. "Dear you got to go in and do your blood work." And every single time I'll sign him in to the same day mental health thing and he'll always flip out or find some reason why he can't and throw a friggin conniption fit like in front of everybody and embarrass himself and all this so we'll like end up not having to you know finish the appointment things. But yeah, he's not currently getting any medical treatment through a physician."

Sarah: "He went, we took him to Topeka VA where he spent a week there and then um, we decided to go he went into a program called the Valor Program which is civilian it's not VA."

Trish: "Just because the VA so bad at ordering prescriptions and they are not about fixing. But he wants to get fixed, he wants his back fixed and no one is taking him seriously. I said I want a spinal doctor. Send him to somebody that knows. They sent him to a neurosurgeon person but they did not go through everything that the other local civilian hospital said. And then now they - we switched hospitals because we were transferring over an hour away so now, we are at a closer hospital so it is like we are starting over. You transfer VA's, it's starting over. We're trying to get this surgery. It is a lot of work to move with a veteran. And they have to do their protocol. We did call an outside spinal institute and they said they would look at him. They need the referral from primary."

VA Respite Program

The Veterans Administration has developed a program for caregivers of veterans who served after 2001. If qualified, caregivers can benefit financially and receive online caregiver training. Although the VA does offer a respite program, caregivers are unable to use this benefit as the veteran will not go to the VA or allow caregivers in the home. Veterans trust only their family to give them care.

Ann: "I know with the caregiver program they offer like for him to go somewhere during that time but he won't go. Like he doesn't do change. He's not going to like hook up with somebody. He's like he's not going to do that. He doesn't like change, he doesn't like to be out of his house. You know that is like his comfort zone."

Meg: "I was entitled to a home health aide but he didn't like anyone to come to the house.
I got about 20 hours a week by the state you know. And um he didn't like having somebody come into the house."

Mary: " The VA preaches to me, and says you know what about respite care and what about someone coming in and helping you clean and he won't go for that, we tried that but he will not

NO want anybody in this house, want anybody dealing with things but me, there is just this trust level you know that he doesn't want that.

Stressors

Caregiving demands are often physically, emotionally, socially, and financially challenging. Respondents perceived their lives to be uncontrollable, unpredictable, and overloaded resulting in stress. Caregivers identified four areas of stress outlined below.

A. Veteran: Dependent Adult

Participants describe the stresses of providing round the clock supervision for an adult who is unable to care for themselves. Caregivers never expected that the veteran would return from serving in the military and be unable to work or be involved in family life

Mary; "My mother is European and my father was military, never combat but he was army and uh so that I was familiar with military life and all that stuff. Never thought I would marry a service member, never thought that I was going to leave Europe at that so, all my training was done in Europe. I sacrificed so much in my life (crying) doing what I am doing, I'll be damned if I'll walk away because all of these years, I fought for him and I am just going to leave? I mean yes there are times when I am not happy in this relationship. You know my role as a wife kind of falls away now. I mean that's a lot we tackle with too. In this whole caregiver – when am I wife and you know it's different. Um it is kind of hard. I just feel basically I don't even feel like his wife anymore. I am his caregiver, his personal assistant. You know I structure his whole day. I mean where is wife mode. If somebody would have told me my life would have been this way. I am telling you right now I would have run for the hills because it is not what you want."

Joy: "When we first met, when we first got together um, I had no idea that he was a current service member, that he was a combat vet. Um all that kind of stuff. That was kept from me for years. Until even after we got married it came out that he had a military commitment, he had seen combat. And all this kind of stuff. I always had a feeling that he was keeping something from me but it wasn't until like we had some, uh we had some situations where his true self came out and that's when I learned that we're not going to be able to be normal. Like we can't just be a normal couple that does normal things. I certainly didn't know that this was what I was going to get uh stuck with basically."

Meg: "This was not supposed to happen. First of all, he was supposed to be a mechanic you know when he got out that fixed airplanes. He's smart and he you know and now he just stays at home and tells me he doesn't feel good. I thought it was going to be just a normal um life. You know where he would come home for short period of time and get married and have grandbabies and life would be all peachy keen. But instead he comes home to stay and he's got a lot going on medically."

Ann: "Part of me wonders why I choose to stick around and like deal with it. You know but then I feel like if I last it will just be worse for him and that he needs me and nobody one else is going to take care of him like that. I do everything. I'm his fiduciary as well so I handle all funds, he won't even go to a grocery store. I do all that, everything."

B. Fighting and Conflict in the Home

Neurobehavioral symptoms in the veteran manifest themselves in physical and abusive behaviors leading to fighting in the home and tension in the caregiver.

Trish: “That’s stressful (laughs) when we are low income, no money that’s stressful. We are at each other’s throat. I always say a good day is not breaking things in the house.”

Joy: “He’ll make it an interpersonal issue if he’s having a health issue so he kind of like amps himself up on it. Sometimes when I get home it just hits the fan for like no apparent reason. I’ve experienced very recently where if he’ll ask me something and then I’ll respond and he’ll say “No you are being disrespectful” and then that will start a whole issue. Then I’ll say “I’m not being disrespectful” and he’ll say “Oh that’s you’re backtalking me” and then it will escalate and sometimes it will kind of get physical but I squash that right away.”

Ann: “There are good days and bad days. There’re days where he fights me on everything. It could even be just like him fighting me taking medicine. I mean he spends like every day just pissed off for no reason. I don’t say anything when he’s like upset about something. I try to just kind of leave it and he’ll like still have a fight with me. Like a really bad fight without me even saying a word.”

C. *Worrying about Veteran Safety*

The stress of wondering if the veteran is safe at home or will harm themselves when the leave the house in a fit of anger.

Sarah: “He would get irritated or he would have a bad day at the treatment facility. I could ask one thing, say something wrong, look the wrong way, say it in a wrong tone and then um everything would hit the fan. Um he would be extremely angry. Um he has angry outbursts. Um he would leave the house. I wouldn’t know where he was at or where he was going, or if he was coming back.”

Ann:” I spend my day making sure that he feels safe and it’s like walking on a lot of egg shells because everything is a fight. Like if I don’t do something correctly, I mean you know it’s just a fight. Memorial Day, he normally chooses to just go and get drunk and I have to go find him and hopefully not pick him up out of jail. The only time I really didn’t have to worry about him was when he was hospitalized.”

D. Children and Parenting

Caregivers expressed being stressed by having to shoulder all of the parenting responsibilities and describe the effect of the veteran’s disability on the children.

Mary: “The kids are missing out on certain things, I mean things that they would like to do with their father. Um Brian does put in the effort on doing things with them um but the kids are ... I always say these kids are- they are so smart about it, they know that when there are functions or something like a holiday well, they will say “Mom we are not going today because of crowds.”

They know how Dad deals with crowds. They understand so what I started or what I have been doing all of their lives is that I overcompensate for their Dad. Um and that is tough too because I got three boys because I have no idea when it comes to fishing for example, you know what I mean. If they want to go fishing, I will take them fishing.

You know I think with me a lot of it as the children are getting older, as I am talking to a lot of other caregivers that have older children now, they are like blaming their mothers "Why did you stay in this relationship with Dad? You don't know what that did to us." I that's kind of my concern, I mean am I damaging them by staying or you know. These are things that kind of pop in sometimes you know. But I mean my children, I have always told been told that children are resilient. You know pride in, they are good in school, they are good little boys. So, I've done something right. You know but with Chris having ADHD and then the doctor says he is showing signs of anxiety now. You know is this being caused by his Dad and uh yeah. Those are things you know I sometimes question."

Sarah: "He would be extremely angry. Um he has angry outbursts. If my daughter happens to be here then of course she' upset as well. You know your daughter is here - you gotta bring this back down to regulation, everything's going to be ok. Um it and then we try to calm down and move on."

Trish: "He was getting upset and I didn't want to him being upset around the children so I said "You know what, we will go to the park and we'll have fun" and give him some time to calm down. I just made sure the kids were ok, it was a bad day yesterday."

Ann: "We sleep in separate rooms. Um my kids and I all sleep in the master bedroom together uh they have their own separate little beds. The 7-year-old is actually home schooled in case I needed anything else to do. We live in a really kind of poor school district. And I just didn't feel safe sending him to school. Honestly not to place blame or anything but I have been with you know my veteran for almost 9 years and I have been almost led to believe that there is no good anywhere in this world, in our town, at my son's school. So, you know I am like almost afraid to send him because of everything I've been said over the years and you know with all the stuff that goes on at school now a day you know. So, I am not blaming him but you know I worry so much. If something happened I would so obviously like responsible that I didn't protect him or something.

I don't leave my husband alone with my children. not that I think he would do anything but I don't know if he's having a fit. I know my little one is a little bit of a handful and I know he really pushes buttons sometimes. You know I can't just risk that. Like my kids are my number one my priority and you know they don't have such a bad life. I'm really good about getting them out if there is an issue."

Theme 4

Self-Care: Finding Time to Care for Self: *"If you don't Take Care of Yourself, you can't Take Care of Anyone Else"*

Stress and Health

The stress of caregiving can lead to physical health deterioration and mental and emotional distress. Caregivers reported feelings of fatigue, anxiety, and feeling helpless and hopeless with one caregiver experiencing secondary PTSD. Multiple, competing demands may lead to chronic multisymptom illness including fibromyalgia or exacerbate chronic conditions such as hypertension. Older caregivers are challenged with trying to care for the veteran while trying to manage their own medical conditions.

Trish: "Yesterday, I can't even remember I am so tired. I am just so worn down. I it almost feels like I didn't sleep at all even though I did sleep. I'm like … I want to cry, I feel tensed up. Emotionally, I'm stressed out. Even myself sometimes I feel like him, throw in the towel or whatever. Spiritually it's like lost a connection (laughs) because I know in my heart ok, I should meditate, pray but it is like um yeah, I just uh feel so much burden and it is hard to slow down.

Heart racing yeah um heart pulsates on the heart because yeah, my doctor says my heart isn't having premature beats and all sorts of things. I don't feel it, I feel more faint, more like light-headed? I don't feel like pounding or something. I haven't heard back from the stress test. I wore the heart monitor the second time, the first monitor I feel a lot of premature beats."

Ann: "I can't stay up all night making sure that he's OK and he's sleeping. I'm like tired too. I have been almost led to believe that there is no good anywhere in this world. A really bad, stressful day - it makes me feel bad and like helpless, it makes me feel worthless, it makes me feel hopeless. Blood pressure wise, like I know I take a blood pressure pill or whatever. You mean walking on eggshells like my blood pressure is rising.

I have been told that I have secondary Post Traumatic Stress Disorder, which basically means that because I have lived so long with someone with such severe PTSD that I now am exhibiting like the same symptoms but in a different way. So, now when I am going to the movies which my husband never does, but when I am going without taking my kids or a friend or whatever I'm sitting all the way at the back because I need to be able to see everybody coming in. I need to be able to have that advantage of being up over everyone. You know I'm not letting anyone behind me that I can't see them. Um that's even like sitting in a restaurant like I sit, if I can pick, I pick the booth in the back where I can see the entrance and I can see the people coming in you know. And uh you know nobody really, I don't think anyone wants to be in a crowd. Like nobody prefers to be in a crowd but I'm getting like anxiety in crowds and if there's like a backpack or something that someone has just set down, I'm like you know "Who's backpack is that like what's going on?" I'm starting to portray those kinds of things.

I don't if it is, I don't remember always being really easily like upset but I don't know if that is my age or having kids. I don't know that I'm like easily like it just doesn't take a lot to upset me. Like I can hold my composure like in front of you if you like are upsetting me but then I will go and like break down really easily by myself. just like being really upset and crying and just feeling like hopeless. Just really upset like I don't know like just I feel really upset I'm just really easily upset like even over little things. Like I just feel like everything is against me almost. It's just like even the littlest disagreement I'm like upset."

Joy: "Both of my parents have notice that I've changed since being with him in dealing with all of this. All of them have notice, siblings have noticed like yes it does affect me for sure, for sure. I tend in my personal like not at home but at work and stuff I find myself being more easily distracted and jumpier and I have a hard time focusing. I um was never anxious like ever, ever in my past. And I find myself having more anxiety about things um now after dealing with him. There's actually a lot of anger that comes with it too. Like that's another thing that I never experienced in the past. Um but for sure I have a lot of it because of this lifestyle. There's a lot of anger there."

Mary: “I suffer from fibromyalgia so when he gets to that point where he gets real irritable, I react to that. My reaction to that is that I go into a full-on flare. Physically what happens if overall just overall pain, my neck starts hurting, I get headaches again, my anxiety flares up. Um and my body just rebels. That’s how I explain it to my doctor. I feel like I am on fire. I move, I move but it is difficult. Because I mean that pain is just unbearable. I was diagnosed 2 years ago. Before these two years I was fine. I didn’t uh nothing stopped me. I was always on the go nothing ... I never got sick. Then I was diagnosed with hypertension. I mean that was something that wasn’t normal for me. Um a lot of stuff changed. I’m not as I can’t do some of the things that I am used to. I am on atenolol, I am on a blood pressure medication for my hypertension and then I take Gabapentin for the nerve pain and then of course I take my supplements my B12 and fish oil so that is what I am currently on.”

Sarah: “I’m a police officer, I am in the process of being medically retired. I was attacked by a dog a few years ago and went through the physical aspects of that. Then while I was going through the physical aspects of that I was not out in the field. out of the blue was told that I was going to have to go back out into the field so be a field officer again. And uh we happened to be on vacation, it was out of the blue and I immediately started having nightmares, a dog attack. And then was approached by a couple of different dogs on our vacation and just it sent me into a tailspin. And um prior to I want to say about a couple of months ago I had been going to our department um therapist, they sent me to a psychiatrist. And did that for probably 8 months I bet and then it came to them saying um I would not be able to go back out in the field. So, then all of it shifts to our retirement board.”

Lynn: “I was sick for a week. I had some kind of a flu so I could not do anything and before that, the end of June I had heart surgery. It’s something that had just recently come up probably in the last year. Um but it got worst faster than they thought. They thought the medication was going to help – I had uh it’s called SVT. I had the heart ablation. I had the ablation therapy. I do have high blood pressure um I have hypothyroid um high blood pressure and then I do take Paxil, and that was mostly because I’m premenopausal.”

Meg: “I am on a CPAP machine at night and oxygen at night. Um and I have pulmonary hypertension and that causes diastolic dysfunction in the heart area. And I was diagnosed with that in 2015. I have a lot of different I have a lot of doctors too, a lot of specialists. I have a lung doctor, a diabetes doctor, a primary care doctor. Um I am doing physical therapy. They diagnosed me with bipolar disorder and anxiety, general anxiety disorder. Last year I ended up I was doing three things in one day and I fell at the third place and I broke my leg. I’m just overwhelmed and I’m tired from all the other issues.”

Self-Care Activities

Caregivers recognize the importance of self-care. Veterans are dependent on them and if they do not take care of themselves, who will care for the veteran. Getting out of the house, walking the dog, or treating themselves to a “spa day” whether soaking in the bath or going and getting their nails done are favorite activities. Caregivers appreciate a full day caregiver retreat where people serve them. Journaling, yoga, deep breathing, mindfulness and crafts are other activities caregivers do to relax. School work was considered an escape and a form of "good stress".

Mary: "I mean I listen more to my body now – now being diagnosed – I don't push myself hard and I will take the time to say I can't do this today. I will just put it on the back-burner um and that is something that I had to learn uh you know am I really going to push through this right now where I am going to be bedridden for the next three days. You know so I am kind thinking what choice is better for me. Um so I've made a lot of lifestyle changes. Um I dropped 40 pounds through nutrition and exercise and um I think I've kind of worked on self-care because I was putting everyone before myself and I've kind learn to um I owe it to myself to be well as well because if I am not well, I cannot be there for the ones that I love so I have made changes.

My outlet is walking I mean I uh have a dog, I take the dog and I will just remove myself for a while. Um I do mindfulness exercises, um I do yoga um I love to garden, I like to be out in the yard. You know just get out there and that is kind of my outlet. I journal, I write down a lot of stuff. Um so that's what I kind of do. I kind of get into my own little self. And I make the time, I am making a conscience effort for making the time to do something just for me.

Lynn: "I think self-care is hard for me. Um and I don't think that I am any different than most women. I think we all kind of suffer from feeling a little guilt when we do self-care. But the longer I've been taking care of him, the more I realize that I have to do that or I'm not going to be any good for him. If you don't take care of yourself, you can't take care of anyone else. And I'm starting to realize that. Like I need – I need to have my time um yeah because if you're all stressed out then you can't really help other people.

I'm not a big exerciser. Um and I do love to cook so I usually make sure that we have fresh food for dinner. Like we might go out maybe once a month, maybe twice a month. But I try really hard to not use processed food and to cook everything from scratch. But that's something that I enjoy, it's not a task for me so I do um I love cooking and like I said I love serving so to me getting up and making sure all the house stuff is done. I've been getting back to reading again, it helps me relax."

Meg: "I like to do baths and sometimes I'll let the water um I sit on a bench because of my limitations physically. I like to soak my feet you know before I give myself a bath and just soak them in the water. I like to make collages and cards and you know that kind of thing so that kind of gets my mind off of stuff. Um there's a game site I get on and play Scrabble or word games.

I did go to a retreat, I went to a spiritual retreat last week. They had a - it was in the paper, in the Catholic newspaper about a place that I always wanted to go and see. It overlooks the Mississippi River and its owned and run by the Jesuit priest and they had a free meal, breakfast, dinner and lunch and they had Catholic mass. I needed that day but I looked at the lady who sat next to me all day and we talked at lunchtime. I told her I don't want to leave. I just want to stay."

Sarah: "My daughter and I did go and get our nails done yesterday, we had a Mommy and daughter day. I will um I religiously get my hair done. If I'm not getting my hair done then people know that something's terribly wrong with me um, I am not in a good place. Um so religiously go get my hair done. I uh what else do I do. I have gone on caregiver retreats. I went to a caregiver luncheon yesterday, So, I try to stay involved with other caregivers. I love to travel; my husband and I actually do travel quite a bit. I love my school, uh I just finished my bachelor's degree after trying to get it done for years. I'm glad I did because it was a lifesaver for me, it gave me meaning and purpose."

Trish: "Today is much better than it used to be and I feel it's because I reached through my own social networks. I go to spouse group. I started taking care of myself. I am trying to like exercise more, trying to walk the dog like even "I am taking the dog out!" And that has been kind of healing for me because I have no children. And that is kind of like my go away time. I also play piano."

Joy: "I have a lot of creative outlets. Um different crafty outlets that I do. I have like other side businesses that I do to help. I do a lot of meditation and I do a lot of things like um around here they have the sensory deprivation sea salt tanks. I read a lot. I keep books with me on uh certain you know spiritual topics. If I'm home then I'll usually get out. I'll need to get out and do something so I'll go take a walk or we've got a lot of parks and things around us so, sometimes I'll take the dogs. Um sometimes if I don't want to get too far away then we got some land and I'll go out on our land and do some type of physical work, prune, weed whatever.

I'll do like a spa day you know, super long shower you know paint my toes. Um those types of things like a beauty treatment. Those will relax me and make me feel better so that's how I'll take care of myself. We both of us eat very healthy. We were sedentary and ate you know crappy food and weren't mindful of all that stuff so, we made lifestyle changes.

Ann: "I do try to work out and not eat a bunch of crap. I do try to take care of myself. I'll try to like come home and unwind in the bath or something. If not, if it's just him and it is not good for me to be home, I try to go do something, whether it's like walk around the park or even just getting my nails done or something. You know like just to focus on me. I just like to go we have a nice park so I go walk around the park um just to like ease my mind and uh get in some exercise too. I try to find uh time during the day to uh work out that's about all I do. I don't have fancy hair, I don't have like really nice clothes. You know I just don't but I do try to work out daily at least Monday through Friday. I'm pretty spiritual. I'm a Christian, I attend church and class.

Self-Care Inhibitors

Although caregivers know the importance of self-care, multiple responsibilities make it difficult to find the time for self-care. Other inhibitors of self-care include lack of energy and motivation, feeling guilty when leaving the family, finding a "babysitter" for children or veteran, or financial restrictions.

Trish: "I should be taking care of myself but it's hard, it's tough -time, energy, scheduling. Babysitting you know who am I going to get to watch my children. Whom am I going to get watch my husband because (laughs) a lot of time it's him more than my children.

Sarah: "We'll schedule something together and go and do it. Um we actually all of us have been trying to go and do a yoga class but then we - it's just life gets in the way and we let other things take that away from us.

Meg: "I think I'm just overwhelmed and I'm tired from all the other issues. I think there is just too much on my plate some days. And um I also think that sometimes money prevents me you know. I'm on just social security disability income and my whole entire check goes to paying the bills"

Mary: “Depending on what is going on in that week, in that month. Doctor’s appointments - I do not have that much time to you know doing the things I like to do, certain outlets.”

Lynn: “Now when I go back to work, I don’t sleep in, I get up when he gets up at 6 and I get all of my stuff done before I go to my Mom’s. So, then I am busier cause I have to get up earlier, I’m not getting as much sleep. So, I don’t take as good care of myself as I should.”

Joy: “Motivation is it. Like really sometimes he really wears me out. And then I’m so worn out after being at work all day dealing with the crew. I mean my crew is great like being away from him constantly worried about him. So, motivation is the first thing that keeps me from doing it. And then just time like it really is.”

Theme 5

Caregiver Peers: Creating a New Community: ***“I am Not Alone”***

Support Systems

Caregivers are not alone in caring for a veteran with invisible wounds of war as they find support from family, friends, and their churches. When caregivers experience the stigma surrounding suicide and mental illness, they turn to a community of caregiver peers who understand their situation.

Stigma

Friends and family do not understand the neurobehavioral symptoms of TBI or PTSD thinking the veteran looks “normal”. There is a stigma surrounding brain injury. Not only do friends and family not understand what the caregivers are going through, they encourage them to leave their “abusive” situation.

Mary: “We have lost a lot of relationships. That is really hard for me especially with his you know with his last suicide attempt. We lost really good friends of ours um because they could not really deal with that. They don’t, they didn’t understand - they you know that was really hard. It was really hard for him because he really loved these people and he just couldn’t understand how somebody could abandon somebody and he had a low point in his life and he would have expected these people to be supportive. But I told Brian you know what - not everybody understands this. Sometimes people come up to him and go: “You look at how long he has been home now and you are still not well?” You know, they don’t get it. You know from the outside he looks normal. I mean we don’t have any – he’s not an amputee or he doesn’t have any physical you know damage to his body. He looks normal.

Ann: “Most of my friends they are supportive, they love me they love my kids they’re obviously like if I call them and needed them, they would like be there. But they’re supportive in the sense of they don’t want me with my husband, if that makes sense. They’re like they don’t understand the situation, they don’t understand PTSD they’re not living with someone with PTSD/TBI. Um so it's like I don't they're like "I don't understand why you don't just leave him. Like you know he treats you guys like crap. He doesn't go to his kids T-ball games, he doesn't go to their karate lessons. He doesn't do nothing for you guys. You know he just causes conflict and sadness". You know so they want they're supportive in me leaving."

Friends, Family and Church Support

Having family close by provides caregivers assistance with day to day tasks. Caregivers also find support from church friends and pastors.

Mary: "We try to surround ourselves – I mean and the good friends we do have, they genuinely did their research and they get him. They get him they understand or when he gets agitated you know they are able to say "Hey Brian -it's OK, it's fine, so what. We will be out somewhere and you know there's a noise and he will startle easily. They will reassure him – you are fine you know."

He's from California so he has his mother, father, and sister, they are supportive. His Mom is a support because she is actually the one that took him to his appointment today. Grandma she helps us out, she takes the 2 little ones to school. She's kind of my support system when I have to have a doctor's appointment with him because I accompany him to all of his doctor appointments because he forgets to ask certain things so she'll sit here with the kids while I am running him to doctor's appointments."

Ann: "When I am really stressed, I try to like just take a breather. If I am able to my parents are like really close. Um my Mom works from home and my Dad he still works but whatever my Mom works from home. So, it's really nice. So, if I am really stressed out if I just call her and say can you take the kids, she'll like 9 times out of 10 is able to do that. So, I'll try to drop the boys off with her for even if it's just an hour or two.

I'm a Christian, I attend church and class. There are some like a couple of men, there are two men specifically um that I call because they are veterans, one is Army and one is Marine like my husband and um they can like kind of talk to him. Yeah so there are guys in the church that I can depend on and I know that if I call them, they would be here and they have in the past."

Lynn: "We have a really strong church that we found um so that helps. I'm still not serving at this church, but Jim is – right away he met a guy who was a veteran. He's one of the elders there, and he's in charge of security, they have security and what they call first responders. He right away got involved in that. And that's helped because he has met so many other men in the church. Now he knows more people than I do. I just feel that that has helped a lot."

Sarah: "I have a really good spiritual base. Um that's usually my saving grace. It is to um either I don't know about necessarily praying but usually you know Hey give me strength God. Help me find a peace here. You know please look after him, help me with my daughter. We have a chaplain that um we both talk to quite a bit that is a support for both of us. He is a care chaplain at our church but he's also a military chaplain. So, um he kind of he understands um both sides so it's, it's really nice to. We do have we have support at our church um we have not been going to church although our support is there. He had two of the pastors, the care chaplain and another pastor come and visit him while um he was inpatient so that's a huge support for both of us. Um, I reached out to them and let them know and they came up and visited him."

Veteran Caregiver Community

Caregivers create their own community of support, surrounding themselves with people who are understanding or other veteran families. Caregivers meet fellow caregivers while sitting in a VA waiting room during veteran appointments. National programs including Operation Family Caregiver, the Dole Foundation Caregiver Fellows program, or the VA Caregiver Support program provide caregivers with online education and support groups.

Trish: "I love my wives spouse group, that meets every week through the vet center. I think that has been really eye opening. We realize we are all married to the same person with different faces. I also do "Give an hour". It's a local therapist in your community. You type in a zip code and you get free therapy in your area. And so, I go to my "give an hour" every week. That's been a lifesaver for me, 100%."

Sarah: "My friends, my good caregiver friends, that's huge for me, huge support. I'm a part of the Elizabeth Dole Foundation, I'm a Dole Fellow, actually that's a huge support for me. I have a non-profit that we started a year ago. My executive team members, my two other part of the executive team, they're both caregivers. We meet every week, it's not only a time that we get together and work, we um we're there for each other too. Um I could call then right now and one of them would be here for me if I needed them. I do not have support from my family so, it's been a huge lifesaver to have them."

Meg: "The case worker that came today. Um she's pretty good. She calls and checks up on me. Um once a month I go to the psychiatrist um the mental health outpatient clinic and I go to group. I've got the life coach; the life coach only talks to me for a half an hour a week. And then she has a group that I get on once a week on Facebook and we call and then talk together in this group you know and it's all ladies. And it's kind of fun you know. I also have a veteran caregiver with the Red Cross, there's three ladies that run groups on there so periodically I'll get in and listen to you know those support groups too on the computer."

Mary: "I have been in the caregiver program since '07, yes, I do get a stipend. I am very connected to other fellow caregivers. Um they are good friends of mine. Um I try to flock to people that are trying to deal with the same situations that I am in. You know I have found that a lot of people in the civilian world do not get where we are coming from, our lifestyle so that is kind of my support. I am connected to Operation Homefront, Wounded Warrior Project, um there is a lot of Facebook support groups that we are connected. I am really connected with the Elizabeth Dole Foundation."

Lynn: "I have a specific friend; her husband is a veteran and pretty much the same issues as far as PTSD and all that kind of stuff. And so, if I'm really feeling like I'm starting to isolate and not talking to people, and kind of pulling away from everything kind of then I can call her and she'll kind of talk me through it. And she gets it. Like a lot of people feel like they can help but if they're not a caregiver of a veteran, it's just hard cause so specific and so it helps to have that person that. And so, we might not talk for a month but she'll call me when she needs the same thing. And we know we can pick up where we left off so that's really good support system.

I do have um Facebook group of caregivers called "Household 6" and um that's a really good place, the moderator for this group is really on top of things and really keeps good control of the group. I know that it is somewhere I can go if I need to vent or if I'm having an issue. And a lot of times you feel like, you're alone. You know like I'm having this certain issue and then when you say it, they're all like "Yep, I get it. My husband does the same thing". It's totally and then all of a sudden, you're like "Hey, so it's not just me". And it's helpful to have that just to know that I'm not alone, this is a common thing."

Ann: "I do have one friend that I actually met at the VA our local VA and she's in a very similar situation. She has 4 kids. And she's living her husband has TBI/PTSD and pretty much the same thing of my husband. And uh same war everything. And so, we've really like it's just crazy. We just met up in the waiting room waiting for our husbands. We are seeing different therapists. We started talking. She had one of her boys I had my littlest boy. We just like hit it off and so she's someone and now our husbands have I wouldn't call it like really good friends but they've taken up to each other. So, now they have each other. And then me and her she's like totally the first person I call like she understands him in a deeper way because she's in the same situation. And then more importantly she's nonjudgmental so she is not going to say well just leave him so it's not like a fit for all uh so she offers better support and she'll come. She's a stay at home Mom. She'll come we can meet up you know and talk and she offers a little bit better insight because she knows more of what is going on and she is living it too."

I'm doing something called Operation Family Caregiver. She zooms me and actually I have a zoom appointment with her tomorrow, it's our finale. And then I'm excited because she said after I complete it like um, I guess I join like a support group on Facebook. Like women or spouses who have um already completed the program here who are you know similar to me. So, I am excited about that. I always like to feel that I am not alone."

Theme 6

Post Traumatic Growth: Learning to Become the PTSD Expert: *"I am Not the Same Person"*

Post Traumatic Stress Disorder (PTSD) and traumatic brain injury (TBI) have been labeled the "invisible wounds" of modern warfare. Caregivers became self-directed learners in order to provide safe and effective care for the veteran. As a result of their new knowledge, they were able to grow and share their expertise with others.

Mary: "Nobody was prepared for what we were getting. I remember the first time that they put him on Seroquel. I wasn't even in the caregiver program then and this man would, he couldn't get off the couch. I thought he had OD'd. I really did and I don't know why I am feeling like this and I go well I almost rushed him to the ER. Well I found out that you know knowing now about the medications you know it can cause these effects. It would have been nice to know going to this appointment to hear that from the doctor that these could be the symptoms of this medication. Now I'm aware of the medication he's on and very dialed in his treatment plan."

Trish: "Through the years I want to say it's better. Um, there was a playing time where because I was lost and didn't know what to do that when needs would happen, I would think that I am on a roller coaster. I learned my own tool. Even though we are on this roller coaster, I always say that the downs are not as bad. I've learned a lot of boundaries. Before, I didn't even know what a trigger was, and what PTSD and what is going on. I am a different person today than I was by keeping up with the education and the classes and meeting other spouses in my shoes."

Ann: “That’s why I wanted to go to school for sociology because I feel I have experience, it’s really all I know how to deal with. I live with a veteran with PTSD/TBI but I feel the spouses need support. I want to somehow help spouses. Like that’s my heart.”

Joy: “Learned a LOT about medical care. I read a lot. I keep books with me on uh certain you know spiritual topics. I keep those, I have amassed quite a collection of books on how to deal with PTS and combat, coming back together and mindfulness and all those types of things. I reference them frequently.

I’m growing and what I’ve gained through my caregiving experience is like that you have to balance love and wisdom. About how to stop issues from becoming exacerbated, how to um refocus energy that they’re giving, how to just be non-reactive and how to move through it.”

Lynn: “I have a greater understanding of “invisible wounds” and am more compassionate than I used to be.”

Theme 7

Motivation: Sacrificial, Unconditional Love: *“LOVE is What Pulls Us Through”*

What caregivers do every day is not easy. Veterans can become verbally abusive and aggressive when neurobehavioral symptoms are triggered. Caregivers question why they stay in this difficult situation especially when friends and family are non-supportive. First, the women say it is their nature to nurture and care for people. Second, they stay because they love their family.

Mary: “I dealt with stroke patients, dementia patients so that’s why I roll- it’s easy for me. My nature is the caretaker. I always took care of people but I question a lot of times why I am putting myself through this. Nobody can understand it – how many times from people have I heard ‘I can’t believe that you’re still married to this man, I can’t believe you are putting up with this’. I talk to a lot of caregivers and a lot of girlfriends of mine that are dealing with, there is just glimpses you get from these men at times where it is just ok that’s the old Ryan you know. I am just I know that when he is like that it is not him.”

Trish: “Positive aspect of caregiving – he is my best friend. Also, I like giving back, that’s my thing. I love helping other veteran resources. It makes me feel good like on the on-line communities. I like to go on and give resources to other families. That makes me feel good.”

Ann: “Part of me wonders why I choose to stick around and like deal with it. First and foremost, before war this was an amazing man. He is I still see that sometimes. It is not very often but I know that loving, caring fun guy is like in there. You know like nobody should have to go to war and deal with and see the things that these guys have dealt with and seen. And I am not even saying they are dealing with it I’m saying like in their minds eyes they are carrying on with their mission. There’s no grieving process you know like they just and then they you know get out and they are just thrown back into society. And that’s not fair. And I do love him. Like I love him, I love what he has done for our country. He’s the father of my children and I am taking care of my kids’ dad so he can be a good dad to them hopefully someday.”

Joy: “I get to be closer to my husband through caring for him. I care for him deeply. I do. And I know who he is besides from the issues. His issues extremely impact his day to day functioning but when there’s not these issues then he’s just I he’s just my soulmate. That’s the thing - I don’t ever want to leave him. But our relationship, if it wasn’t for all of this military trauma and fallout from his military service. Like everything was fine until his military stuff started coming out. And that’s why I stay. Because I know who he is underneath all of that.”

Sarah: “Women in general, we have this innate you know nurturing part about us anyway and that’s what we do. Caregiving can bring you closer to your loved ones and also give you experience to help others. Although working on the non-profit is busy, it’s a busy that I like, it’s enjoyful. It’s a passion of mine. I love doing it. I love meeting other people, I love helping other people.”

Lynn: “I just remember laying there and they were getting ready to wheel me into the operating room and he just stood there staring at me and it just broke my heart because he had this look like “what am I going to do if something happens to you?” And I can’t forget that face and so that has really like made me think, I’ve got to take better care of myself because that face, he made was just so pitiful that I thought if something happens to me, what is he going to do? What’s going to happen to him.”

Meg: “My son and I we are a team…I am probably the only person in the world that knows and understands him bests and puts up with him and he me. LOVE is what pulls us through.”

Summary

Findings from the analysis of the qualitative interviews validated, complimented and expanded upon the results of the online survey. In the quantitative study, severe forgetfulness and severe anxiousness in the veteran were the most frequently neurobehavioral symptoms reported by the caregivers. These symptoms were positively associated with physical and emotional caregiver burden. Caregivers demonstrated anxiety and depressive symptoms, and were moderately to very stressed by the caregiving demands. Higher perceived stress and depression scores were correlated with poorer cardiovascular health. Caregivers did receive emotional and informational support but tangible support if the caregiver became ill was lacking.

By triangulating study methods, the qualitative interviews transform the numerical data into a description of the daily experience of living with a veteran with invisible wounds of war. Whereas the online survey described problems and challenges, the interviews added insight as to the positive aspects of caregiving and strengths displayed by the caregivers.

As affective and cognitive symptoms in the veteran occurred unpredictably and caregivers “walked on eggshells” to avoid triggering maladaptive or abusive behaviors in the veteran. These symptoms sometimes cause sleep disturbances in both the veteran and caregiver. Forgetfulness and depression rendered the patient unsafe to home alone requiring constant supervision by the caregiver. Forgetfulness and sensitivity to noise prevented the veteran from engaging with his children and partnering with the caregiver in parenting responsibilities. When away for home, caregivers worried that the veteran would remain safe. Symptoms of anger and irritability led to fights and conflicts in the home.

Unique to caregivers of veterans with service related injuries is learning to advocate for the veteran and navigate the complex Veteran’s Administration (VA) Healthcare System. Caregivers described this as “fighting through the system” to connect with the healthcare team or find resources for new medical problems that arise in the veteran. Although programs have been developed to provide financial and educational support to caregivers, the veteran’s anxiety and distrust of the system prevent caregivers from taking advantage of in-home support or respite programs.

The review of the literature found that the stresses of caregiving can lead to physical health deterioration and mental and emotional distress with caregivers developing chronic conditions such as fibromyalgia, hypertension, or anxiety and PTSD. Caregivers recognized the importance of taking care of themselves. Caregivers believed that they needed to remain healthy because their family members depended on them. Tension arising from the emotional burden of caregiving was relieved by practicing yoga, mindfulness, or walking outside in parks or the neighborhood. Lack of time and energy were identified as self-care inhibitors by the caregivers.

Caregivers found meaning, purpose, and support by interacting with other caregivers, either online or finding local caregiver support groups. Caregivers experienced the stigma surrounding mental illness and physical disability, often losing families and friends due to their lack of understanding and support. As a result, caregivers surrounded themselves with new friends, developing a community of peers.

Finally, instead of becoming overwhelmed by the challenges of caring for a veteran with invisible wounds of war, caregivers became self-directed learners choosing to learn and grow from this experience demonstrating post traumatic growth. Several caregivers, desiring to help others, pursued professional degrees becoming experts in the field. Although as one caregiver said: “what I do every day is not easy”, caregivers remained committed to their relationship and motivated by love for the veteran and their families.

Chapter 6 Discussion

These findings demonstrate the relationship between cardiovascular health in mothers and wives caring for post 9/11 veterans with either TBI or PTSD. In this chapter, the qualitative results will be integrated into the discussion of the quantitative findings. Limitations of the study and nursing implications and conclusions will be presented.

Description of the Sample

Consistent with the FACES[1] and Hidden Heroes[2] samples, caregivers in this study were similar to other post 9/11 caregivers in that they were white, non-Hispanic college/trade school educated, and employed outside the home. Compared with Faces and Hidden Heroes samples, substantially more caregivers were spouses than parents. It is likely that this contributed to other demographic differences with these previous studies. Specifically, in the current study participants were younger, living with veteran, and parenting children under 18 years of age. The majority of caregivers in this study reported adequate income, enough to make ends meet; in contrast with previous studies.[3-5] This difference could be attributed to the fact that a greater number of veterans in this study were receiving disability compensation and the caregivers were receiving a financial stipend. Higher household income may have accounted for higher social support scores for participants in this study. Half of the veterans in this study were diagnosed with both PTSD and TBI; in contrast, other studies have restricted enrollment to veterans with TBI.[1,4,6]

Veteran Neurobehavioral Symptoms and Caregiver Burden

Previous studies have focused on the characteristics and unique challenges of military and service member caregivers and the psychosocial aspects of caregiver burden.[1,2,7,8] Caregivers in this study reported spending the most time providing emotional support for the veteran, managing emotional and behavioral problems (e.g. anxiety, depression, flashbacks, nightmares, irritability, anger, and aggression), performing additional household tasks for the veteran, and monitoring veteran's neurobehavioral symptoms. Ramchand and colleagues found that caregivers of post 9/11 veterans spent more time assisting the veteran to cope with stressful situations, avoid triggers of anxiety and antisocial behavior, and helping with other emotional and behavioral problems, compared with pre-9/11 and civilian caregivers.[2] The vast majority of post 9/11 caregivers are providing help to a veteran with TBI or a comorbid mental health diagnosis, such as PTSD or depression. Therefore helping the veteran to manage emotional and behavioral problems is consistent with findings of other studies.[7,9-11] Caregivers in this study also spent time navigating the healthcare and legal systems (advocacy) as reported in other studies.[1,2,8,10]

Symptoms related to TBI, PTSD and other comorbidities including depression, anxiety, stress, and sleep disturbances often overlap. Caregivers often need to help the veteran manage these symptoms without the benefit of a medical diagnosis. Family caregivers are instrumental in reporting troubling symptoms to clinicians to obtain an accurate diagnosis.[11] Veterans' neurobehavioral symptoms rated as severe or very severe by the caregiver on the quantitative survey included: forgetfulness and difficulty concentrating, difficulty falling asleep, feeling anxious, feeling depressed, irritability and poor frustration tolerance. The experience of living with a veteran trying to deal with these symptoms on a daily basis was described in the qualitative interviews and in other qualitative studies.[10-12]

Forgetfulness, poor concentration, and difficulty making decisions were described by the caregivers as particularly difficult symptoms to deal with as they prevented the veteran from safe, independent living. Caregivers needed to be available to remind veterans about medications or appointments. One mother was unable to move to a retirement community, as her veteran son was unable to manage the house on his own. These findings are consistent with the findings of a qualitative study by Saban and colleagues.[11]

Episodes of Irritability, uncontrolled anger, and physical and verbal abuse by the veteran led to the creation of an adverse family environment in the home. Caregivers described these outbursts as being explosive and unpredictable; identifying triggers of these explosive behaviors was not always possible. Constant arguments with the veteran created a stressful environment in the home. Participants in this study describe learning to remain non-reactive and to suppress any emotion they may be feeling during these outbursts. Further, they reported that sometimes it was best to leave the situation until the veteran was able to calm down and regain composure. These findings are consistent with other qualitative studies.[5,10-12]

Consistent with the literature,[11,12] caregivers recognized the effects of these neurobehavioral symptoms on the children. Caregivers felt that they were unable to safely leave children alone with the veteran. Forgetfulness may cause the veteran to forget to pick children up from school or children's play may trigger symptoms in the veteran. Caregivers expressed being stressed by dual caregiving roles for both the veteran and children. They felt that they were shouldering all of the parenting responsibilities by themselves and were grieved that the veteran was not able to fully participate in the children's lives. Participants in this study describe the importance of making the home a safe place for all family members. Recognizing the needs of children of service members and veterans, researchers have developed a program to promote family resilience.[13]

Caregiver Burden and Caregiver Psychosocial Health Outcomes

Cognitive and affective neurobehavioral symptoms were positively correlated with caregiver burden in this study. Further, emotional burden included spending a great amount of time worrying about the veteran and needing to supervise the veteran. Caregivers are burdened by the constant hypervigilance required to manage these behavioral symptoms. Consistent with the findings of Kratz and colleagues,[12] caregivers in this study worried about the veteran's safety when he was left alone. They expressed concerns regarding the possibility of another injury or "something going wrong" when they left the veteran alone in the house. Unique to this study, participants worried about the veteran committing suicide, as several veterans had a history of suicidal attempts. Future research studies are needed to examine the role of family caregivers in suicide prevention and interventions to promote hope for both the veteran and caregiver.

Utilizing structural equation modeling, Griffin and colleagues reported that neurobehavioral symptoms in the veteran were associated with poorer caregiver mental health (anxiety and depression) through increased caregiver burden.[9] Consistent with the findings of other studies, participants in this study demonstrated anxiety and depressive symptoms that would be classified as needing further evaluation.[2,8,9,14,15] Caregivers in this study felt particularly anxious about avoiding emotional and behavioral triggers in the veteran; they described these feelings like "walking on eggshells". This phrase was also used by the participants in the study by Kratz and colleagues.[12] Training programs that assist caregivers in managing emotional or cognitive problems in the veteran reduced anxiety, depression, and caregiver burden.[16,17]

Consistent with other studies,[4,8,10-12] participants in this study described being moderately to severely stressed and overwhelmed by caregiver role demands. Stressors included lack of alone time, constant medical appointments, multiple role responsibilities and frequent disruptions of their daily schedule. Participants in the study by Carlozzi and colleagues expressed a lot of anger related to lack of availability, accessibility, and ease of navigating the VA healthcare system.[10] Other investigators have found that family caregivers not trained in navigating the complex VA healthcare system endorsed higher depression than those who received training.[16] Caregivers in this study described being more stressed and frustrated by lack of coordinated care, difficulty qualifying for appropriate benefits, getting timely appointments for the veteran, and feeling disconnected from the healthcare team. Participants in this study describe spending a great deal of time advocating for the veteran and coordinating care within the VA healthcare system and community.

No other studies described the significant role caregivers play in disease management and care coordination in this population of veterans with mental health conditions and cognitive impairment. Grebeldinger and Buckley examined the role of parish nurses in meeting the needs of family caregivers and found that parish/faith community nurses were an effective bridge between the medical team and the family caregiver. In this study, caregivers described benefitting from the physical presence of the parish nurse and information and resources provided by the parish nurse.[18] The role of faith-based organizations in providing support for veterans and their families is an area for future investigations.

Care of the veteran with invisible wounds of war requires effective case management and complex care coordination.[19] Much of the care previously done by professional nurses is now done at home by family members.[20] When the VA healthcare system could not meet the needs of the veteran, participants in this study were left with the responsibility of finding and coordinating care in the community. Mobile health technologies for disease specific self-management have been developed by the VA for patients and their caregivers. , In a study by Frisbee caregivers most frequently used the mobile apps that assisted them with care coordination and not the VA PTSD coach that would help the veteran with neurobehavioral symptom management.[21] Over half of the veterans in this study had both TBI and PTSD and available treatments for comorbid mental and physical health conditions are largely fragmented and disease specific. Further research is needed to evaluate integrated, family centered approaches of care that promotes improved symptomatic and functional outcomes.[22]

Consistent with other studies, [2,12,23] caregivers reported a need for instrumental (e.g., cooking, cleaning, running errands) and professional support and respite. In the study by Kratz and colleagues, caregivers expressed the desire for assistance with daily duties and monitoring the veteran so they could run errands or take personal time.[12] Although the VA offers in-home support and a respite program, veterans in this study would not allow strangers in their home or refused to leave their home for an in-patient VA respite stay. Caregivers in this study described the need to provide a safe, home environment in order to prevent triggers of PTSD that retraumatized the veteran. Veterans trusted only their spouse or parent to provide care and became anxious when their loved was not involved. Veterans had difficulty making new friendships or developing their own peer support community. Principles of trauma informed care included: (1) safety, (2) trustworthiness and transparency, (3) peer support, (4) collaboration and mutuality, and (5) empowerment, voice, and choice.[24] Future research protocols should incorporate these principles when designing family-centered, community-based interventions that support caregivers.

Caregivers in this study described experiencing social isolation and the loss of friendships as a result of caregiving, a finding that is consistent with other studies.[2,10-12] Lack of family support has been associated with poor health.[4] Social support has been shown to be protective against caregiver burden and poor mental health.[9,25] Consistent with the findings of Saban and colleagues,[11] caregivers in this study found support from their caregiver peers and the veteran community.

Caregiver Burden and Caregiver Physical Health Outcomes

Whereas studies to date have focused on the psychosocial aspects of caregiver burden, researchers are now examining the relationship between caregiver burden and physical health outcomes. The purpose of this study was to examine the relationship between caregiver burden and cardiovascular health and to identify facilitators and inhibitors to heart health self-care. Consistent with other studies,[2,4,11,12] participants in this study reported that disruption in their daily schedule and multiple caregiving responsibilities left them with a significant lack of personal time inhibiting their ability to engage in self-care activities. Higher scores for depressive symptoms and perceived stress were correlated with poorer heart health for the participants in this study. In the VIRGO study, young women with acute myocardial infarction exhibited higher levels of depression and stress and poorer physical and mental health than young men.[26] Consistent with the findings of Mosca and colleagues,[27] women in this study were not aware of healthy levels of cardiovascular risk factors and most did not know their numbers. Over half of the participants in this study did not know their blood pressure, glucose or cholesterol levels. However, they demonstrated ideal cardiovascular health in that they were non-smokers and exercised regularly.

Over the past twenty years, fewer people have ideal cardiovascular health (CVH) scores because of decreases in those with ideal status of body mass index (BMI), blood glucose and serum cholesterol levels as reported in the Framingham Offspring Study.[28] The majority of the participants in this study had a BMI that would be classified as overweight or obese but as they were young women many did not think that they were at risk for heart disease. This finding is consistent with other reports that young women are unaware of the increasing cardiovascular heart disease (CHD) death rates in US women 35-54 years of age.[29] This increase in death rates in this age group is believed to be due, at least in part, to the effects of the obesity epidemic.[29] Awareness that personal CVD scores were not healthy was positively associated with women taking action to lower risk in family members and themselves.[27] Although participants in this study cited family caregiving responsibilities and lack of time as a barrier to heart health, they recognized the importance of taking care of themselves so that they could take care of their families. In a qualitative study of women veterans, the participants stated that building trust in a peer support intervention, the need for a flexible approach, and the need for behavior change accountability were important factors to consider when designing a heart health promotion intervention.[30]

Caregivers in this study did not focus entirely on the negative impact of caring for a veteran with invisible wounds of war. Consistent with the findings of other studies,[4,7,12,25] caregivers found their role as pleasurable and rewarding. In the qualitative interviews, participants observed growth in their ability to handle daily difficulties and challenges, developed feelings of hopefulness and determination, and a stronger friendship with the veteran that enabled them to meet the challenges of managing invisible wounds of war. Future clinical and research programs should aim at enhancing protective factors that promote resilience, wellness and growth in the veteran and their families.

Limitations

Limitations of this study include the cross-sectional design, small sample size, and convenience sampling. Subjects were recruited from only two veteran caregiver support groups. The sample may have been biased towards those who were comfortable with using technology or were already connected to VA benefits. Because of these factors, the findings of this study are not generalizable to the veteran caregiver population at large, in particular nonwhite or less educated caregivers, or caregivers of veterans getting care in the community. While the online survey allowed for national recruitment of participants, this method inhibited the ability to collect biological data. As participants needed to remain anonymous, the Involvement Evaluation Questionnaire (IEQ) was revised to remove sensitive data regarding self-harming or abusive behaviors by the veteran. As a result of this missing data, both the AHA Life's Simple Seven and the IEQ were modified limiting the generalizability of the results to the general veteran population. Future studies may benefit from face to face interactions with the research staff to collect biological data and implement protocols that protect the safety and privacy of research subjects. Prospective, longitudinal designs that examine families as systems are recommended as studies to date have been restricted to cross-sectional, convenience sample.

Implications and Conclusions

Family caregivers increasingly are expected to provide complex care at home to wounded veterans. As a result, they often sacrifice their own physical and mental health. Caregivers in this study demonstrated anxiety and depression that would be classified as needing further evaluation. Blood pressure is a simple indicator of cardiovascular health and emotional distress and a beneficial tool to assist clinicians in identifying women at cardiovascular risk and emotional distress that warrants further evaluation.

Utilizing a mixed method research approach generated a greater understanding of the effects of caregiving on the cardiovascular health of mothers and wives caring for veterans with invisible wounds of war. Social media and the internet are useful investigative tools but are not as effective as face to face interactions for both the clinician and researcher.

Caregivers in this study benefitted from peer support but expressed the need for ongoing input from professional providers and to be considered an integral member of the veteran's healthcare team. The effectiveness of a family centered; peer-professional co-facilitated intervention is a topic for future research. Results of this study will be used to design a health promotion intervention for caregivers utilizing principles of community based participatory research and trauma informed care.

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Appendix A

Stress and Self-Care Interview Guide

1. I am interested in hearing about your experience as a caregiver. Tell me about a normal day but let's be specific: What happened yesterday?
   Prompt: How did it begin?

   Prompt: Then what happened?

   Prompt: Was it your typical day like? How was yesterday different or similar to your typical day?

2. What made it good? What made it bad? How did it rate compared to your most stressful day?

   Prompt: Tell me about your most stressful day? What made it stressful?

   Prompt: How did you react physically? Emotionally? Spiritually?

3. How do you think that stress impacts your health?

   Prompt: How do you react when you are stressed?

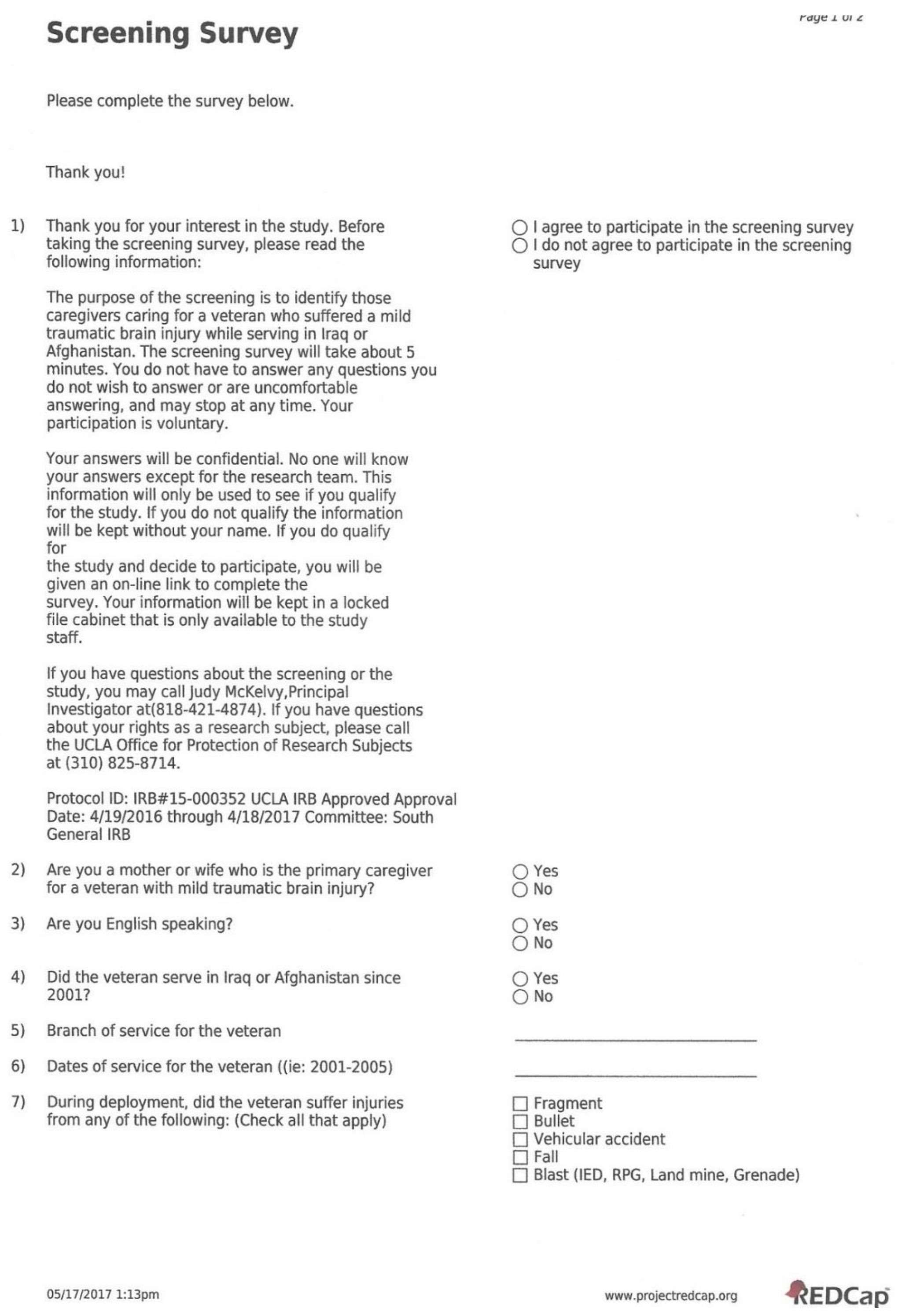
   Prompt: What do you do or not do when you are stressed?

   Prompt: Who or what in your world is supportive or helpful in reducing stress?

4. You take care of your veteran; how do you take care of yourself?
   Prompt: What helps you take care of yourself?

   Prompt: What prevents you from caring for yourself?

Addendum B Screening Survey



Screening Survey

Please complete the survey below.

Thank you!

1)	Thank you for your interest in the study. Before taking the screening survey, please read the following information: The purpose of the screening is to identify those caregivers caring for a veteran who suffered a mild traumatic brain injury while serving in Iraq or Afghanistan. The screening survey will take about 5 minutes. You do not have to answer any questions you do not wish to answer or are uncomfortable answering, and may stop at any time. Your participation is voluntary. Your answers will be confidential. No one will know your answers except for the research team. This information will only be used to see if you qualify for the study. If you do not qualify the information will be kept without your name. If you do qualify for the study and decide to participate, you will be given an on-line link to complete the survey. Your information will be kept in a locked file cabinet that is only available to the study staff. If you have questions about the screening or the study, you may call Judy McKelvy,Principal Investigator at(818-421-4874). If you have questions about your rights as a research subject, please call the UCLA Office for Protection of Research Subjects at (310) 825-8714. Protocol ID: IRB#15-000352 UCLA IRB Approved Approval Date: 4/19/2016 through 4/18/2017 Committee: South General IRB	○ I agree to participate in the screening survey ○ I do not agree to participate in the screening survey
2)	Are you a mother or wife who is the primary caregiver for a veteran with mild traumatic brain injury?	○ Yes ○ No
3)	Are you English speaking?	○ Yes ○ No
4)	Did the veteran serve in Iraq or Afghanistan since 2001?	○ Yes ○ No
5)	Branch of service for the veteran	______________________________
6)	Dates of service for the veteran ((ie: 2001-2005)	______________________________
7)	During deployment, did the veteran suffer injuries from any of the following: (Check all that apply)	☐ Fragment ☐ Bullet ☐ Vehicular accident ☐ Fall ☐ Blast (IED, RPG, Land mine, Grenade)

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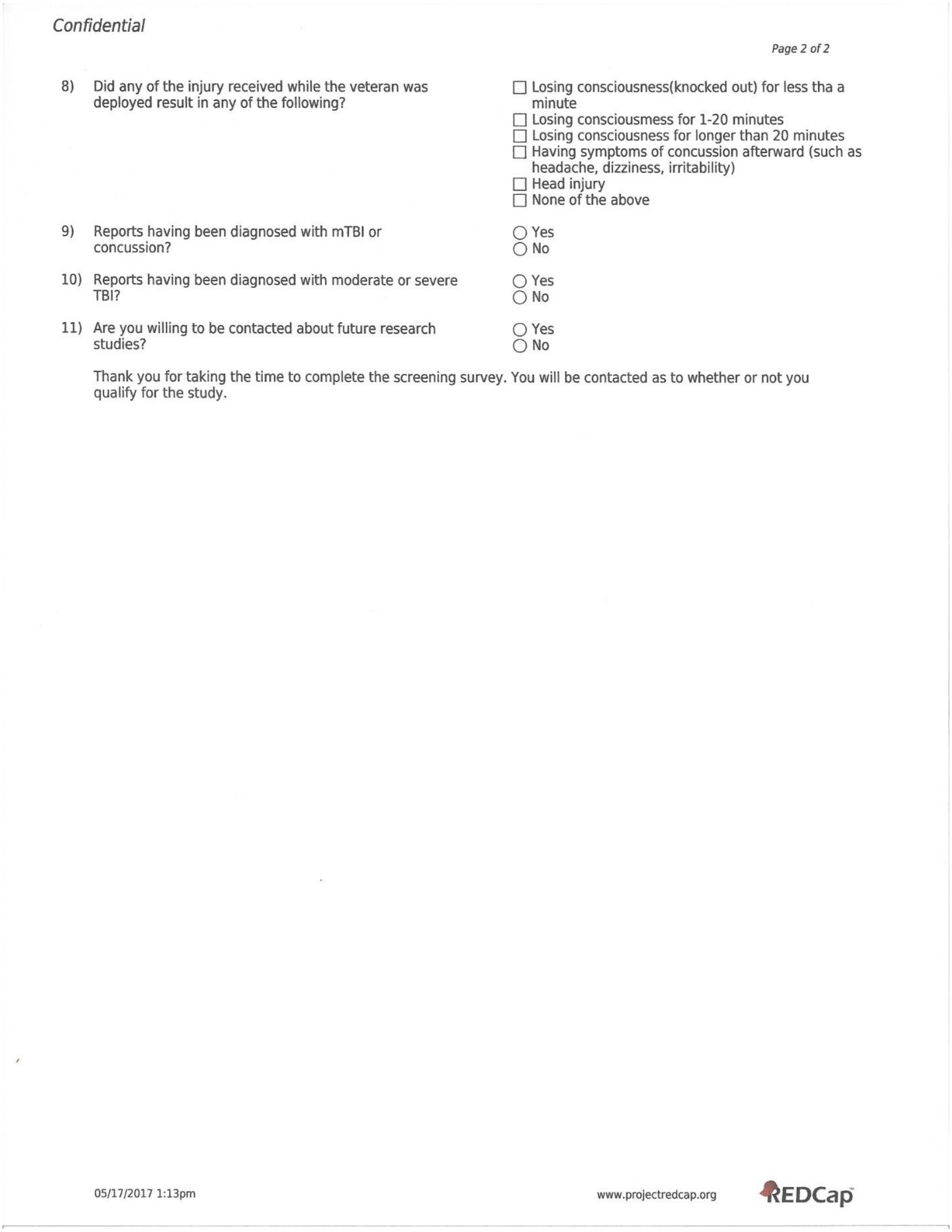
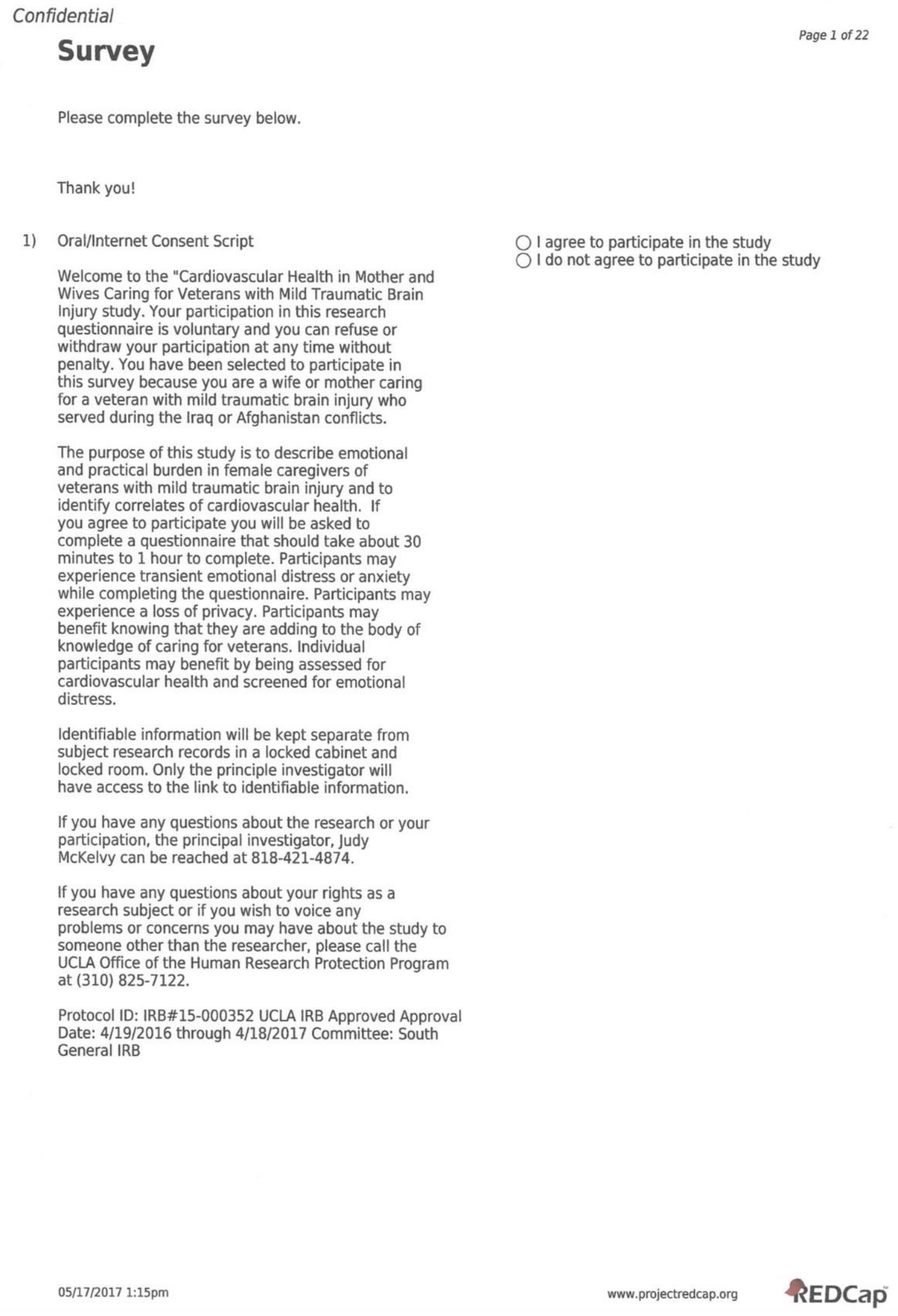


8)	Did any of the injury received while the veteran was deployed result in any of the following?	☐ Losing consciousness(knocked out) for less tha a minute ☐ Losing consciousmess for 1-20 minutes ☐ Losing consciousness for longer than 20 minutes ☐ Having symptoms of concussion afterward (such as headache, dizziness, irritability) ☐ Head injury ☐ None of the above
9)	Reports having been diagnosed with mTBI or concussion?	○ Yes ○ No
10)	Reports having been diagnosed with moderate or severe TBI?	○ Yes ○ No
11)	Are you willing to be contacted about future research studies?	○ Yes ○ No

Thank you for taking the time to complete the screening survey. You will be contacted as to whether or not you qualify for the study.

Addendum C Quantitative Survey



Confidential

Page 1 of 22

Survey

Please complete the survey below.

Thank you!

1) Oral/Internet Consent Script

○ I agree to participate in the study
○ I do not agree to participate in the study

Welcome to the "Cardiovascular Health in Mother and Wives Caring for Veterans with Mild Traumatic Brain Injury study. Your participation in this research questionnaire is voluntary and you can refuse or withdraw your participation at any time without penalty. You have been selected to participate in this survey because you are a wife or mother caring for a veteran with mild traumatic brain injury who served during the Iraq or Afghanistan conflicts.

The purpose of this study is to describe emotional and practical burden in female caregivers of veterans with mild traumatic brain injury and to identify correlates of cardiovascular health. If you agree to participate you will be asked to complete a questionnaire that should take about 30 minutes to 1 hour to complete. Participants may experience transient emotional distress or anxiety while completing the questionnaire. Participants may experience a loss of privacy. Participants may benefit knowing that they are adding to the body of knowledge of caring for veterans. Individual participants may benefit by being assessed for cardiovascular health and screened for emotional distress.

Identifiable information will be kept separate from subject research records in a locked cabinet and locked room. Only the principle investigator will have access to the link to identifiable information.

If you have any questions about the research or your participation, the principal investigator, Judy McKelvy can be reached at 818-421-4874.

If you have any questions about your rights as a research subject or if you wish to voice any problems or concerns you may have about the study to someone other than the researcher, please call the UCLA Office of the Human Research Protection Program at (310) 825-7122.

Protocol ID: IRB#15-000352 UCLA IRB Approved Approval Date: 4/19/2016 through 4/18/2017 Committee: South General IRB

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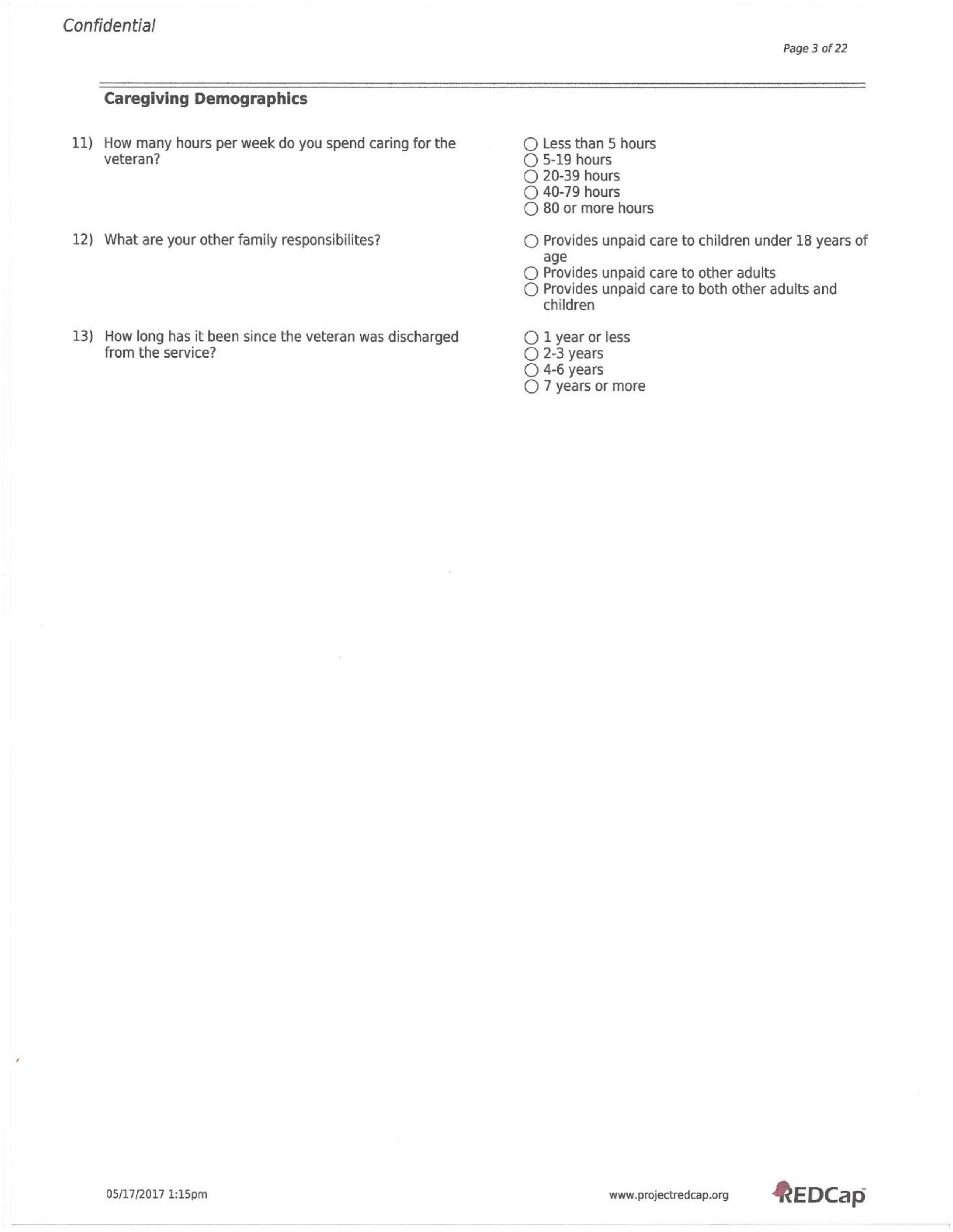
Demographics

2)	Age (years)	______________________
3)	Ethnicity	○ 1 Hispanic ○ 2 Non-Hispanic
4)	Race	○ 1 Caucasian ○ 2. African American ○ 3 Asian ○ 4 Native Hawaiian or Pacific Islander ○ 5 American Indian or Alaska Native ○ 6 Identified more than 1 race ○ 7 Other ○ 8 Unknown
5)	Current Employment status	☐ Working full-time ☐ Working part- time ☐ Student full-time ☐ Student part-time ☐ Housewife ☐ Retired ☐ Disabled (Please check all that apply)
6)	Highest year of education	○ Grade School ○ High School ○ Technical School ○ College ○ Graduate School
7)	Considering the amount that comes into your household for you to live on, would you say you:	○ Are comfortable, have more than enough to make ends meet ○ Have enough to make ends meet ○ Do not have enougn to make ends meet
8)	Do you have a regular source of healthcare? (Physician, Nurse Practitioner, Clinic)	○ Yes ○ No
9)	Do you have any of the following types of health insurance? (Check all that apply)	☐ Private Health Insurance ☐ Regular Medicare ☐ Supplemaental Medicare ☐ Medicaid ☐ Veterans Administration ☐ None
10)	How long have you been the primary caregiver for the veteran with traumatic brain injury?	○ 1 year or less ○ 2-3 years ○ 4-6 years ○ 7 years or more



Caregiving Demographics

11)	How many hours per week do you spend caring for the veteran?	○ Less than 5 hours ○ 5-19 hours ○ 20-39 hours ○ 40-79 hours ○ 80 or more hours
12)	What are your other family responsibilites?	○ Provides unpaid care to children under 18 years of age ○ Provides unpaid care to other adults ○ Provides unpaid care to both other adults and children
13)	How long has it been since the veteran was discharged from the service?	○ 1 year or less ○ 2-3 years ○ 4-6 years ○ 7 years or more

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Patients with traumatic bain injury may display a number of neurological and behavioral symptoms. The purpose of this inventory is to track symptoms over time.

Please rate the following symptoms with regard to how often you have noticed the symptoms or the veteran has complained of the symptom in the last 2 weeks.

1 = None - rarely present
2= Mild - occassionally present but it does not disrupt the veteran's activities
3 = Moderate - Often present, occassionally disrupts activies
4 = Severe - Frequently present and disrupts activities
5 = Very Severe - Almost always present and veteran is unable to function at work, school, or home due to this problem.

		None	Mild	Moderate	Severe	Very severe
14)	Feeling dizzy	○	○	○	○	○
15)	Loss of balance	○	○	○	○	○
16)	Poor coordination, clumsy	○	○	○	○	○
17)	Headaches	○	○	○	○	○
18)	Nausea	○	○	○	○	○
19)	Vision problems, blurring, trouble seeing	○	○	○	○	○
20)	Sensitivity to light	○	○	○	○	○
21)	Hearing difficulty	○	○	○	○	○
22)	Sensitivity to noise	○	○	○	○	○
23)	Numbness or tingling in parts of body	○	○	○	○	○
24)	Change in taste or smell	○	○	○	○	○
25)	Loss of appetite or increased appetite	○	○	○	○	○
26)	Poor concentration, can't pay attention, easily distracted	○	○	○	○	○
27)	Forgetfulness, can't remember things	○	○	○	○	○
28)	Difficulty in making decisions	○	○	○	○	○
29)	Slowed thinking, difficulty in getting organized, can't finish things	○	○	○	○	○
30)	Fatigue, loss of energy, getting tired easily	○	○	○	○	○
31)	Difficulty falling or staying asleep	○	○	○	○	○
32)	Feeling anxious or tense	○	○	○	○	○
33)						

	Feeling depressed or sad	○	○	○	○	○
34)	Irritablity, easily annoyed	○	○	○	○	○
35)	Poor frustration tolerance, feeling easily overwhelmed by things	○	○	○	○	○

This group of questions is about the tasks and activities that you do to help the veteran. For each of the following acitivities, please choose how much time you spend and how difficult each activity is for you to do.

36)	1a. Time spent on medical or nursing treatments: (giving medications, skin care, dressings, etc)	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
37)	1b. Difficulty of medical or nursing treatments?	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
38)	2a. Time spent assisting with personal care (bathing,toileting,getting dressed, feeding, etc)?	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
39)	2b. Difficulty assisting with personal care?	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
40)	3a. Time assisting with walking, getting in and out of bed, exercises, etc?	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
41)	3b. Difficulty assisting with walking, getting out of bed, exercises:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
42)	4a. Time spent providing emotional support "being there" for the veteran?	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
43)	4b. Difficulty providing emotional support?	○ Extremely difficult ○ Very Difficult ○ Moderately Difficult ○ Slightly Difficult ○ Not difficult
44)	5a. Time watching for and reporting veteran's symptoms, watching how the veteran is doing, monitoring the veteran's progress:	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None

45)	5b. Difficulty monitoring symptoms or progress:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
46)	6a.Time spent providing transportation or "company" (driving, riding along with veteran, going to appointments, driving veteran around for errands, etc):	○ A great amount ○ A Large amount ○ A moderate amount ○ A small amount ○ None
47)	6b. Difficulty accompanying or driving veteran:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
48)	7a. Time spent managing veteran's finances, bills, and forms related to the veteran's illness:	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ 5. None
49)	7b. Difficulty managing finances:	○ Extremely Difficult ○ Very Difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
50)	8a. Time spent performing additional household tasks for the veteran (laundry, cooking, cleaning, yard work, home repairs, etc):	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
51)	8b. Difficulty performing additional household tasks:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
52)	9a. Time spent performing additional tasks outside the home for the veteran (shopping for food and clothes, going to the bank, running errands, etc)	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
53)	9b. Difficulty tasks outside the home:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
54)	10a. Time spent structuring/planning activities for the veteran (recreation, rest, meals, things for the veteran to do, etc)	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None

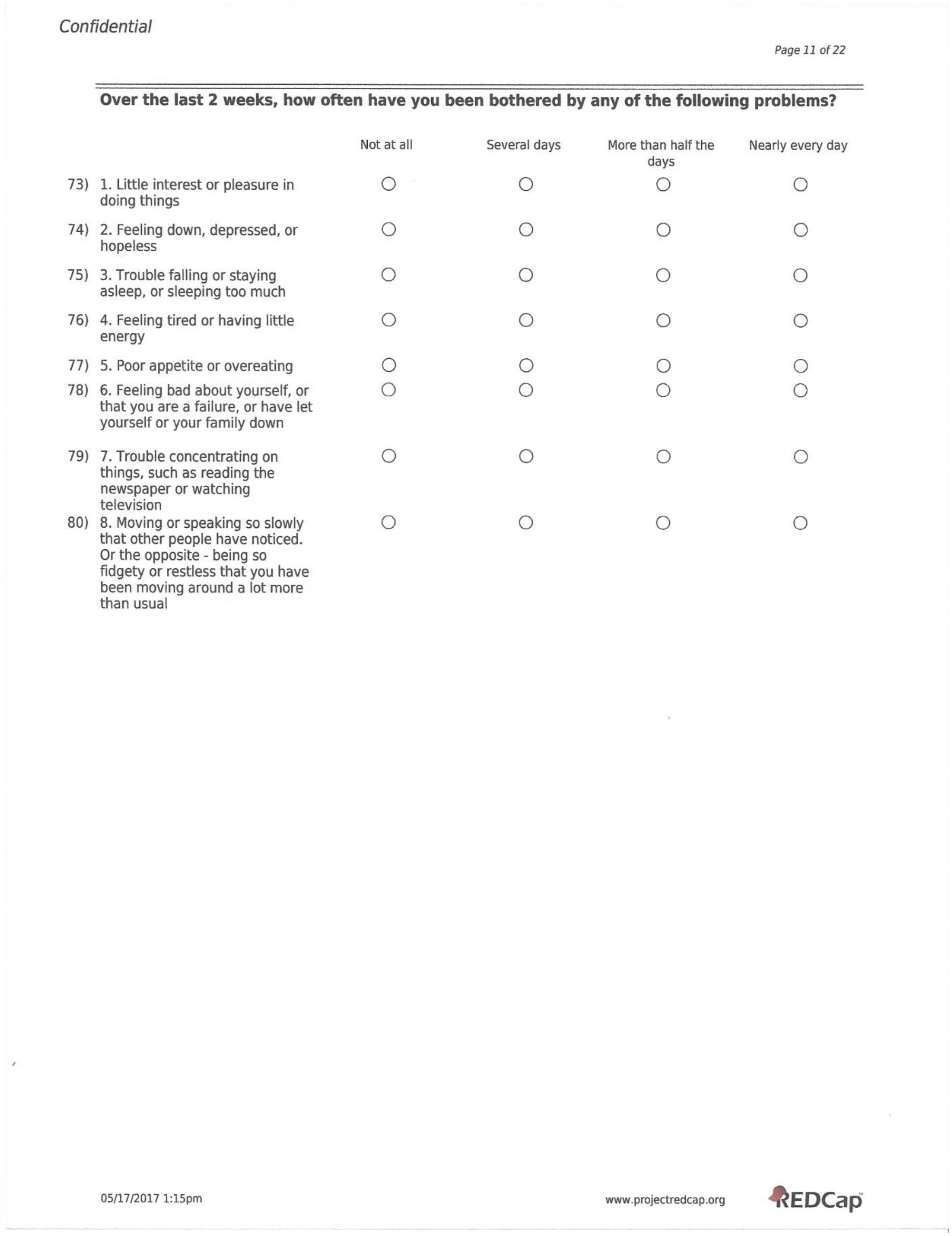
55) 10b. Difficulty planning activities:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
56) 11a. Time spent managing behavior problems (moodiness, irrtability, confusion, memory loss, etc)	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
57) 11b. Difficulty managing behavior:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
58) 12a. Time spent finding and arranging someone to care for the veteran while you are away:	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
59) 12b. Difficulty finding someone to care for veteran while away:	○ Extremely difficult ○ Vary difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
60) 13a. Time with communication (helping the veteran with the phone, writing or reading, eplaining things, trying to understand what the veteran is trying to say, etc):	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
61) 13b. Difficulty helping with communication:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
62) 14a. Time spent coordinating, arranging, and managing services and resources for veteran (scheduling appointments, arranging transportation, locating equipment and services, finding outside help):	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None
63) 14b. Difficulty coordinating, arranging, and managing services:	○ Extremely difficult ○ Very difficult ○ Moderately difficult ○ Slightly difficult ○ Not difficult
64) 15a. Time spent seeking information and talking with doctors, nurses, and other professional health care workers about the veteran's condition and treatment plans:	○ A great amount ○ A large amount ○ A moderate amount ○ A small amount ○ None

65) 15b. Difficulty seeking information from healthcare professionals:

○ Extremely difficult
○ Very difficult
○ Moderately difficult
○ Slightly difficult
○ Not difficult

Over the last 2 weeks, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
66) 1. Feeling nervous, anxious, or on edge	○	○	○	○
67) 2. Not being able to stop or control worrying	○	○	○	○
68) 3. Worrying too much about different things	○	○	○	○
69) 4. Trouble relaxing	○	○	○	○
70) 5. Being so restless that it is hard to sit still	○	○	○	○
71) 6. Being easily annoyed or irritable	○	○	○	○
72) 7. Feeling afraid as if something awful might happen	○	○	○	○



Over the last 2 weeks, how often have you been bothered by any of the following problems?

		Not at all	Several days	More than half the days	Nearly every day
73)	1. Little interest or pleasure in doing things	○	○	○	○
74)	2. Feeling down, depressed, or hopeless	○	○	○	○
75)	3. Trouble falling or staying asleep, or sleeping too much	○	○	○	○
76)	4. Feeling tired or having little energy	○	○	○	○
77)	5. Poor appetite or overeating	○	○	○	○
78)	6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	○	○	○	○
79)	7. Trouble concentrating on things, such as reading the newspaper or watching television	○	○	○	○
80)	8. Moving or speaking so slowly that other people have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual	○	○	○	○

Below is a list of problems and complaints that individuals sometimes have in response to stressful life experiences. Please read each one carefully and then rate how much you have been bothered by that problem in the last month.

		Not at all	A little bit	Moderately	Quite a bit	Extremely
81)	Repeated, disturbing memories,thoughts, or images of a stressful experience from the past?	○	○	○	○	○
82)	Repeated, disturbing dreams of a stressful experience from the past?	○	○	○	○	○
83)	Suddenly acting or feeling as if a stressful experience were happening again (as if you were reliving it)?	○	○	○	○	○
84)	Feeling very upset when something reminded you of a stressful experience from the past?	○	○	○	○	○
85)	Having physical reactions (e.g heart pounding, trouble breathing or sweating) when something reminded you of a stressful experience from the past?	○	○	○	○	○
86)	Avoid thinking about or talking about a stressful experience from the past or avoid having feelings related to it?	○	○	○	○	○
87)	Avoid activities or situations because they remind you of a stressful experience from the past?	○	○	○	○	○
88)	Trouble remembering important parts of a stressful experience from the past?	○	○	○	○	○
89)	Loss of interest in things that you used to enjoy?	○	○	○	○	○
90)	Feeling distant or cut off from other people?	○	○	○	○	○
91)	Feeling emotionally numb or being unable to have loving feelings for those close to you?	○	○	○	○	○

92)

	Feeling as if your future will somehow be cut short?	○	○	○	○	○
93)	Trouble falling or staying asleep?	○	○	○	○	○
94)	Feeling irritable or having angry outbursts?	○	○	○	○	○
95)	Having difficulty concentrating?	○	○	○	○	○
96)	Being"super alert" or watchful on guard?	○	○	○	○	○
97)	Feeling jumpy or easily startled?	○	○	○	○	○

The questions in this scale ask you about your feelingsand thoughts during the LAST MONTH. Please rate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular wa, but rather indicate the alternative that seems like a reasonable estimate.

	Never	Almost never	Sometimes	Fairly often	Very often
98) In the last month, how often have you been upset because of something that happened unexpectantly?	○	○	○	○	○
99) In the last month, how often have you felt that you were unable to control the important things in your life?	○	○	○	○	○
100) In the last month, how often have your felt nervous and "stressed"?	○	○	○	○	○
101) In the last month, how often have you dealt successfully with day to day problems and annoyances?	○	○	○	○	○
102) In the last month, how often have you felt that you were effectively coping with important changes that were occuring in your life?	○	○	○	○	○
103) In the last month, how often have you felt confident about your ability to handle personal problems?	○	○	○	○	○
104) In the last month, how often have you felt that things were going your way?	○	○	○	○	○
105) In the last month, how often have you found that you could not cope with all the things that you had to do?	○	○	○	○	○
106) In the last month, how often have you been able to control irriations in your life?	○	○	○	○	○

107)

In the last month, how often have you felt that you were on top of things?	○	○	○	○	○
108) In the last month, how often have you been angered because of things that happened that were outside of your control?	○	○	○	○	○
109) In the last month, how often have you found yourself thinking about things that you have to accomplish?	○	○	○	○	○
110) In the last month, how often have you been able to control the way you spend your time?	○	○	○	○	○
111) In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	○	○	○	○	○

Please read each one carefully and indicate how often in the PAST 4 WEEKS:

	Never	Sometimes	Regularly	Often	Almost always	Choose not to answer
112) Have to encourage the veteran to take proper care of herself/himself (e.g. washing, bathing, brushing teeth, combing hair)?	○	○	○	○	○	○
113) Have you helped the veteran take care of herself/himself?	○	○	○	○	○	○
114) Have you ever encouraged the veteran to eat enough?	○	○	○	○	○	○
115) Have you encouraged the veteran to undertake some kind of activity (e.g. go for a walk, have a chat, hobbies, household chores)?	○	○	○	○	○	○
116) Have you accompanied the veteran on some kind of outside activity because he/she did not dare go alone?	○	○	○	○	○	○
117) Have you ensured that the veteran has taken the required medicine?	○	○	○	○	○	○
118) Have you ensured that the veteran received sufficient sleep?	○	○	○	○	○	○
119) Have you carried out tasks normally done by the veteran (e.g. household chores, financial matters, shopping, cooking)?	○	○	○	○	○	○
120) Have you encouraged the veteran to get up in the morning?	○	○	○	○	○	○
121) Has the veteran disturbed your sleep?	○	○	○	○	○	○
122) Has the atmosphere been strained between you both as a result of the veteran's behavior?	○	○	○	○	○	○
123) Has the veteran caused a quarrel?	○	○	○	○	○	○
124) Have you been annoyed by the veteran's behavior?	○	○	○	○	○	○

125)

Have you heard from others that they have been annoyed by the veteran's behavior?	○	○	○	○	○	○
126) Have you been able to pursue your own activities and interests (e.g. work, hobbies, sports, visits to family and friends)?	○	○	○	○	○	○
127) Have you worried about the kind of help/treatment the veteran is receiving?	○	○	○	○	○	○
128) Have you worried about the veteran's general health?	○	○	○	○	○	○
129) Have you worried about how the veteran would manage financially if you were no longer able to help?	○	○	○	○	○	○
130) Have you worried about the veteran's future?	○	○	○	○	○	○
131) Have you worried about your own future?	○	○	○	○	○	○
132) Has the veteran's brain injury problem been a burden to you?	○	○	○	○	○	○
133) Have you gotten used to the veteran's brain injury problem	○	○	○	○	○	○
134) Have you felt able to cope with the veteran's brain injury problems?	○	○	○	○	○	○
135) Has your relationship with the veteran changed since the onset of the brain injury?	○	○	○	○	○	○

People sometimes look to others for compantionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
136) Someone you can count on to listen to you when you need to talk	○	○	○	○	○
137) Someone to give you information to help you understand a situation	○	○	○	○	○
138) Someone to give you good advice about a crisis	○	○	○	○	○
139) Someone to confide in or talk to about yourself or your problems	○	○	○	○	○
140) Someone whose advice you really want	○	○	○	○	○
141) Someone to share your most private worries and fears with	○	○	○	○	○
142) Someone to turn to for suggestions about how to deal with a personal problem	○	○	○	○	○
143) Someone who understands your problems	○	○	○	○	○
144) Someone to help you if you were confined to bed	○	○	○	○	○
145) Someone to take you to the doctor if you needed it	○	○	○	○	○
146) Someone to prepare your meals if you were unable to do it yourself	○	○	○	○	○
147) Someone to help with daily chores if you were sick	○	○	○	○	○
148) Someone who shows you love and affection	○	○	○	○	○
149) Someone to love and make you feel wanted	○	○	○	○	○
150) Someone who hugs you	○	○	○	○	○
151) Someone to have a good time with	○	○	○	○	○
152) Soemone to get together with for relaxaton	○	○	○	○	○
153) Someone to do something enjoyable with	○	○	○	○	○

154)

Someone to do things to get your mind off things	○	○	○	○	○

FOR WIVES OF VETERANS ONLY

Please complete if you are the wife caring for a veteran with mild traumatic brain injury. This questionnaire deals with your own perception of you and your partner's life together. For each question, please select your response.

155) 1. How often do you discuss or have considered divorce, separation, or terminating your relationship?

○ All the time
○ Most if the time
○ More often than not
○ Occassionally
○ Rarely
○ Never

156) 2. In general, how often do you think that things between you and your partner are going well?

○ All the time
○ Most of the time
○ More often than not
○ Occassionally
○ Rarely
○ Never

157) 3. Do you confide in your mate?

○ All the time
○ Most of the time
○ More often than not
○ Occassionally
○ Rarely
○ Never

158) 4.This question asks about the differenct degrees of happiness in your relationship. The middle point, "happy" represents the degree of happiness of most relationships. Please select the description that best describes the degree of happiness, all things considered, of your relationship.

○ Extremely unhappy
○ Fairly unhappy
○ A little unhappy
○ Happy
○ Very happy
○ Extremely happy
○ Perfectly happy

159) 1. How tall are you?

____
(in inches)

160) 2. What is your weight?

____
(in pounds)

161) 3. What is your zip code?

____

162) 4. Have you been diagnosed by a healthcare provider with any of these conditions:
a. Coronary Heart Disease/chest pain
b. Heart attack
c. Heart failure
d. Stroke/TIA
e. Vascular disease
f. Congenital heart defects

○ Yes
○ No

163) 5. Do you have diabetes? (Type 1 or Type 2)

○ Yes
○ No

164) 6a. How many minutes of moderate physical activity do you get in a week?

All types of activity can be counted such as gardening, walking, bicycling.

____
(Moderate intensity: a person doing moderate intensity aerobic activity can usually talk but not sing during activity)

165) 6b. How many minutes of vigorous physical activity do you get in a week?	________________________________ (Vigorous intensity: a person doing vigorous activity cannot say more than a few workds without pausing for a breath)
166) How many cups of fruit do you eat per day? 1 cup of fruit equals: a large banana 1 medium pear or grapefruit 1 small apple 8 large strawberries 15 grapes or 1/2 cup of raisins	○ 0 ○ .5 ○ 1.0 ○ 1.5 ○ 2 ○ 2.5 ○ 3.0 ○ 3.5 ○ 4.0 ○ 4.5 ○ 5.0 ○ 5.5 ○ 6.0 (0 to 6 cups)
167) 8. How many cups of vegetables do you eat in an average day? (0 to 6) 1 cups of vegetables equals: 1 large bell pepper or ear of corn 1 medium potato or a large sweet potato 1 cup of cooked greens 2 cups of raw green (lettuce, spinach 2 medium carrots or 12 baby carrots 2 larde stalks of celery	○ 0 ○ .5 ○ 1 ○ 1.5 ○ 2 ○ 2.5 ○ 3 ○ 3.5 ○ 4 ○ 4.5 ○ 5 ○ 5.5 ○ 6 (0 to 6 cups)
168) 9. Do you ear 2 servings or more of fish per week? (A serving of fish is 3.5 ounces - approximately the size of a deck of cards)	○ Yes ○ No
169) 10. Do you eat 3 ounces or more of whole grains daily? Examples: 1 slice of whole grain bread 1 cup of 100% whole grain cold cereal 1/2 cup of whole grain hot cereal 1/2 cup of wheat pasta, brown rice 3 cups of popcorn	○ Yes ○ No
170) 11. Do you drink less than 36 ounces (450 calories) of beverages with added sugar weekly? Examples: Non diet soda Lemondade 1 teaspoon of jelly, jam, or sugar 1 teaspoon of honey 1 cup sweetened cereal Pastries, cake, cookies, pies Daily desserts	○ Yes ○ No

171) 12. Do you eat less than 1500 mg of sodium daily? Answer yes if you do 2 of 3: a. Avoid eating prepackaged processed foods or eat foods low in sodium b. Avoid eating out c. Cook at home without adding salt	○ Yes ○ No
172) 13. What is your systolic (top number) blood pressure? (Leave blank if you do not know)	____________________ (90 to 210)
173) 14. What is your diastolic (bottom number) blood pressure? (Leave blank if you do not know)	____________________ (50 to 130)
174) A. Blood Pressure	☐ I don't know my blood pressure ☐ I take meds to lower my blood pressure
175) 15. What is your cholesterol? (Leave blank if you do not know)	____________________ (40-400)
176) A. Cholesterol	☐ I don't know my cholesterol ☐ I take meds to lower my cholesterol
177) 16. What is your fasting blood sugar? (Leave blank if you do not know)	____________________ (50 to 500)
178) A. Fasting blood sugar	☐ I don't know my fasting blood sugar ☐ I take medication to lower my blood sugar
179) 17. Do you smoke?	○ Current ○ Quit 1-12 months ago ○ Quit more than 12 months ago ○ Never smoked
180) Some caregivers describe that event the most challenging or stressful expereinces may have "a silver lining". Please describe any aspects of caregiving that you consider positive.	____________________

If you experience any emotional distress or anxiety after completing the survey, please contact your primary care physician, your county mental health department, or the VA Caregivers Support Line at 1-855-260-3274 (Monday-Friday 8:00am-11:00pm EST and Saturday 10:30 am - 8:00pm EST)).

Addendum D Analysis Domain Template

Interview Question	**Domain**
Q1. Tell me about yesterday and was it a typical day?	**Normal Day Activities** **(Work)**
Q2. Was yesterday a good or bad day and how did it rate to your most stressful day?	**Stressors**
b. How did you react physically? Emotionally? Spiritually?	**Stress Bodily Reactions**
Q3. How do you think stress impacts your health?	**Health** **(Rest)**
b. How do you react to stress, what do you do or not do?	**Stress Response/Actions**
c. Who in your world is supportive or helpful in reducing stress?	**Caregiver Supports** **(Relationships)**
Q4. What helps you to take care of yourself?	**Self-Care Facilitators**
b. What prevents you from taking care of yourself?	**Self-Care Inhibitors**
Q5. Anything to add	