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A Mixed Methods Inquiry of Caregivers of Veterans with Sustained Serious "Invisible" Injuries in Iraq and/or Afghanistan

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A Mixed Methods Inquiry of Caregivers of Veterans with Sustained Serious “Invisible”
Injuries in Iraq and/or Afghanistan

by

Bina Ranjit Patel

A dissertation submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy
School of Social Work
College of Behavioral and Community Sciences
University of South Florida

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Burden

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DEDICATION

This dissertation is dedicated to my family, especially my father, Ranjit Patel. He instilled the value of higher education in me since I was a little girl and did not settle for anything less despite culturally based gender biases. Education was not an option, but a requirement. He worked night and day, 7 days a week, in pursuit of our happiness. He is forever loved and forever in my heart. I know he is always looking over me.

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ABSTRACT

Currently, there are approximately 1.1 million caregivers who are caring for veterans who have served in the military following September 11 (9/11), 2001 (Ramchand et al., 2014). In this study, a mixed methods analysis of post 9/11 caregivers enrolled in the North Florida South Georgia Caregiver Support Program was completed with a convenience sample of 172 participants for quantitative analysis which included 16 participants for the phenomenological query. Correlations, t-tests, and ANOVAs were used to determine the associations among race, gender, age, caregiver type, diagnosis, tier level, and the presence of children in the home with caregiver burden as measured by the Zarit caregiver burden inventory (ZBI). T-tests resulted in a significantly higher ZBI with caregivers who had children in the home ($M = 6.84$; $SD = 3.21$) versus those who did not ($M = 5.57$; $SD = 2.75$), $t(160) = -2.36$, $p = .02$. An ANOVA was conducted across caregiver role (parent, spouse, significant other and other) and the ZBI and a significant difference was found ($F[3, 159] = 1.59$, $p < .01$, with spousal caregivers having a significantly higher ZBI score ($M=6.83$; $SD=3.10$) than parental caregivers ($M = 4.46$; $SD=2.70$).

The phenomenological research focused on shared lived experiences of post 9/11 caregivers of seriously injured veterans, including their experiences with the Caregiver Support Program, the impact of having children in the home, and the utilization of technology and online support with caregiving. Differences between spousal and parental caregivers were also explored. The caregivers' shared experiences resulted in 22

major themes which included family adjustment, subjective demands, coping techniques, social support, Veterans Affairs (VA) and Department of Defense (DOD) services, self-care, intimacy, role strain, financial resources, and life course changes as the most prevalent. Caregivers and their families had a difficult time adjusting post injury, particularly with subjective demands. Caregivers relied mainly on their own coping mechanisms to adapt to their new role and did not find social support to be helpful with caregiving. Spousal caregivers tended to have more difficulty adjusting than did parental caregivers, which was also found in the quantitative study. While the Caregiver Support Program provided many services that were helpful to the caregivers, including a financial stipend, they wanted additional services which included additional financial support and services while citing issues with program implementation and staffing as major barriers. Children added complexity to the caregiving relationship and increased burden. Children displayed behavioral changes, mostly negative, but some positive such as giving both the caregiver and the veteran a sense of purpose. Lastly, technology and online support with caregiving was used more often than not with mixed feelings about the technology and its trustworthiness; with parents not utilizing these resources as much as spousal caregivers. The study concludes with implications for current and future social work practice and research, as well as the study's strengths and limitations.

CHAPTER 1: INTRODUCTION

Since September 11, 2001 (9/11), over two million American troops have been deployed to the Middle East to one of the longest volunteer fought conflicts in American history (Department of Defense [DOD], 2011). America's troops consist of one percent of this country's population and many wounded military personnel are returning home from the Middle East (DOD, 2011). Post-Traumatic Stress Disorder (PTSD), and Traumatic Brain Injury (TBI), together, have been called the "signature" and/or "invisible" injuries of the Iraq and Afghanistan Wars (Fairweather & Garcia, 2007; Tanielian et al., 2013). According to the DOD, between 2000 and 2013, 273,859 U.S. forces have been diagnosed worldwide with a TBI and nine percent and 27% of veterans have self-reported symptoms of PTSD and depressive symptoms, respectively (Tanielian et al., 2013). The influx of injured returning veterans is only expected to increase as President Obama has announced the gradual return of all American soldiers from Iraq and Afghanistan. With this influx of returning combat veterans also comes an increase in the need for caregivers to assist these veterans with adjustment and reintegration into society.

Ramchand et al. (2014) estimates that currently 1.1 million people are caring for veterans who have served after 9/11. These caregivers are unique in that they are likely to care for younger and non-white veterans, and they assume a caregiving role for longer periods of time with little or no social support (Ramchand et al., 2014). Such caregivers are more likely to be in the workforce and care for veterans who are suffering from both

mental health and substance misuse disorders. They are also more likely to use mental health supports/services for themselves (Ramchand et al., 2014).

Inevitably, these family caregivers experience a role shift from being a spouse, mother, daughter, partner, friend to being that of a caregiver. Caregivers play an important part in the veteran's recovery, yet little is known about them, as previous research on caregivers mostly focused on older adults (Beckham, Lytle, & Feldman, 1996; Hayes et al., 2010; Tanielian et al., 2013). Earlier studies demonstrate some distinct differences between caregivers of older adults and veteran caregivers (Link & Palinkas, 2013; Tanielian et al., 2013), however a recent study suggests that civilian and pre 9/11 veteran caregivers are actually more similar than previously thought and that post 9/11 veteran caregivers are a distinct group when compared with other caregivers (Ramchand et al., 2014).

This chapter provides a brief synopsis of characteristics of caregivers in general and then describes veteran caregiver characteristics. Caregiver burden as well as the caregiver objective and subjective demands are described to give the reader a sense of how caregiving can lead to stress/strain. The VHA's Caregiver Support program for veteran caregivers is explained as this was developed in response to caregiving demands; the chapter also overviews why veterans with invisible injuries need caregivers. The chapter concludes with the purpose of the study and the research questions being examined.

Role of the Caregiver

Literature on caregivers of adults suggests that socioeconomic and demographic characteristics may play a vital role in caregiver adaptation. Caregivers that are

Caucasian, females, spouses, younger, and from a lower socioeconomic status have higher rates of burden (Navaie-Waliser, Spriggs, & Feldman, 2002). Living with the care recipient has also been associated with higher levels of strain, isolation, psychological and physical burden on the caregiver (Brodaty & Hadzi-Pavlovic, 1990). These characteristics can potentially be risk factors for Iraq and Afghanistan veteran caregivers. Spouses tend to experience higher levels of strain and sacrifice more in their lives in order to provide care. They prefer not to utilize paid caregiver services or other resources as these services tend to increase their level of strain due to the lack of control on caregivers provided and hours they are available (Zarit & Zarit, 2007). Men tend to have lower levels of strain as they view caregiving as a task, whereas women attach emotionally to caregiving which results in a greater impact on their well-being (Navaie-Waliser et al., 2002; Zarit & Zarit, 2007). Based on the literature, it is plausible that many Iraq and Afghanistan caregivers may experience caregiver burden, but more research is needed regarding how demographic characteristics affect caregiver burden in these new caregivers (Link & Palinkas, 2013; Tanielian et al., 2013).

Veteran Caregivers (VCG)

Post 9/11 caregivers are referred to in the literature as a distinctive group of caregivers (Ramchand et al., 2014). According to a comparison study of 465 veteran caregivers (VCG) from all eras and conflicts and 1,307 civilian caregivers, the average age of caregivers was 48 and they typically have provided care for 4.6 years (National Alliance for Caregiving [NAC], 2010) whereas post 9/11 caregivers' average age was 38 and have provided care for longer periods of time as they typically start providing care at younger ages (Tanielian et al., 2013). Previous VCG studies identified that 80% of

veterans live in the same households with their caregivers, with 96% of caregivers being women and 70% of those being wives (NAC, 2010), whereas 40% of post 9/11 caregivers are males with 33% being spouses (Ramchand et al., 2014). In non-military caregiver (NMCG) populations, 65% of caregivers are women with 6% being wives (NAC, 2010). Caregiver burden was compared with VCG and NMCG populations and 65% of VCG reported caregiver burden versus 31% of NMCG. The study also found that 60% of veterans were suffering from PTSD and 70% with depression/anxiety, both of which were significantly higher than non-military care recipients, where only 28% of care recipients reported any mental health disorders (NAC, 2010). Post 9/11 caregivers are similar in that 52% provide care to a veteran with PTSD and a total of 64% provide care for a veteran with PTSD and substance abuse issues combined (Ramchand et al., 2014). About 95% of caregivers who care for a veteran with PTSD reported that they helped the veteran with mood regulation and 47% of these were the sole uncompensated caregiver in the home compared to 34% of the NMCG population (NAC, 2010).

The toll on the VCGs is also significant as they suffer more emotionally, physically, and psychologically than NMCGs (Ramchand et al., 2014; Tanielian et al., 2013). Financial burden has also been a repeated theme in caregiver burden with all veteran populations (Beckham et al., 1996; Jordan et al., 1992) including Iraq and Afghanistan caregivers (Ramchand et al., 2014) who are caring for a veterans with PTSD (Hayes et al., 2010).

Together these statistics demonstrate that VCG are far more burdened and are dealing with more complex issues when compared to the NMCG populations. This is especially true for post 9/11 caregivers, as current research points to even worse

outcomes for this newer group of caregivers compared to other VCG's in terms of health, employment, and family adjustment (Ramchand et al., 2014). These caregivers also tend to have younger children and strained marital relationships with their spouses (Link & Palinkas, 2013; Ramchand et al., 2014; Sayers, Farrow, Ross, & Oslin, 2009; Tanielian et al., 2013). Furthermore, since the veterans and their caregivers tend to be younger, these caregivers care for longer periods of time than the NMCG populations.

Caregiver Burden

Since there is limited research on post 9/11 caregiver experiences, other caregiver studies provide definitions and a foundation which can be built upon. Caregivers have been providing informal care for their loved ones in the form of short term care (during an illness or injury) and long term care when caring for someone with chronic conditions that require assistance. Historically, women were not in the workforce and therefore care was typically provided by women (Zarit & Zarit, 2007). Today, more and more women are in the workforce and family sizes are smaller, reducing the number of people available to provide care, and they provide countless hours of informal care to their loved ones (Fine, 2011; Zarit & Zarit, 2007). As result of the increased commitments families are facing, caregiver burden has also increased. Caregiver burden can manifest in physical and psychological symptoms (Fine, 2011; Griffin, Friedemann-Snchez, Hall, Phelan, & van Ryn, 2012; Zarit & Zarit, 2007). Borg and Hallberg (2006) indicated that caregivers frequently reported a need for caregiver support including: financial relief (salary or compensation), respite, caregiver advice and support, nursing assistance, and home health aide/homemaker services. Caregiving can be viewed as a normal part of any relationship in short spurts, however caregiver burden begins to manifest when

caregiving becomes chronic in nature and overwhelms the relationship, whether it is with a spouse or other family member. What was once a reciprocal relationship becomes unbalanced (Pearlin, Mullan, Semple &, Skaff, 1990).

Objective and Subjective Caregiver Burden

Caregiver burden is viewed as a phenomenon that cannot be measured or understood by a single domain or item, but includes a multitude of factors. It can be affected by a variety of characteristics including gender, income, support, coping, relationship quality, and level of care needs (Carretero, Garces, Rodenas & Sanjose, 2009; Fine, 2011; Zarit & Zarit, 2007). Caregiver burden can be separated into objective and subjective burden (Carretero et al., 2009; Clay et al., 2013; Fine, 2011; Zarit & Zarit, 2007).

Objective burden

Objective burden can be categorized according to the level of disability of the care recipient, or the presence of cognitive and behavioral problems the care recipient experiences, but typically these issues tend to contribute less to the overall strain experienced by caregivers (Clay et al., 2013; Zarit & Zarit, 2007). The consequences of objective burden can be reported as the lack of free time, diminished hours of work or loss of work and less social interactions (Carretero et al., 2009; Clay et al., 2013).

Subjective burden

Subjective burden, on the other hand, is measured as the caregiver's perception about how the disability impacts their lives, their identity, and their relationships, and therefore has a much more profound impact on the caregiver's physical and psychological health and well-being (Clay et al., 2013; Zarit & Zarit, 2007). Subjective

burden negatively affects a caregiver's sense of self and self-esteem, how competent they feel, and their evaluation of expertise in caregiving (Carretero et al., 2009).

Both objective and subjective burden in combination operationalize the areas in which burden can be experienced and also where focus should be placed when providing interventions and services for post 9/11 caregivers. The Veterans Health Administration (VHA) understood the need for assistance for caregivers and developed a program that not only addressed the financial burden of caregiving, but also the emotional consequences of caregiving. This program is called The Caregiver Support Program (CSP). The CSP was developed with interventions aimed at reducing the consequences of objective burden such as loss of income and work hours, and subjective burden consequences by providing support and access to services within the VHA that can alleviate some of these issues.

The Caregiver Support Program

The Caregivers and Veterans Omnibus Health Services Act (2010) signed by President Obama on May 5th, 2010 is a progressive and unprecedented act that aims to provide support to caregivers of veterans. As a direct result of this policy in May 2010, the VHA developed the Caregiver Support Program (See Appendix A) to assist caregivers of veterans who were seriously injured post 9/11 with benefits. The Caregiver Support Program (CSP) offers caregivers a stipend, health insurance, and counseling for the caregivers if approved.

The CSP targets some of the critical issues that caregivers face when providing care for a loved one in the home. The program not only alleviates some of the financial burden that caregivers repeatedly report in the literature, but also focuses on the medical

and psychological needs of caregivers by providing health insurance for those caregivers that do not have any and by providing mental health counseling for the caregiver at the VHA. Finally, the benefit includes at least 30 days of respite care, yearly. The CSP is unprecedented as only veterans were previously allowed to receive care at the VHA, but now caregivers are receiving mental health counseling and other supports at the VHA.

Background and Context

Why “invisible” injuries require caregiver

In order to understand the unique challenges that post 9/11 caregivers must deal with, a closer look at the population of veterans they care for can provide some insight into the day to day issues they face. Caregivers are essential in assisting veterans with navigating the complex VHA system: transporting/managing appointments, instrumental activities of daily living (IADL) and activities of daily living (ADL) assistance, medication management, legal and financial advocacy, crisis management, stabilization of the veteran until they can receive treatment, and completing and following up on the numerous forms that need to be completed in order to determine benefits/eligibility.

The February 2014 casualty report from the DOD states that there were 51,895 wounded in action (DOD Casualty Report, 2014), but these estimates do not include those suffering from “invisible” injuries (Tanielian et al., 2013). It is estimated that one in five Iraq and Afghanistan veterans are returning with major depression or posttraumatic stress disorder (PTSD) (Tanielian & Jaycox, 2008) while 22% are returning with some form of brain injury (Summerall, 2008). Tanielian et al. (2013) estimate that up to 30% of military personnel that were deployed to Iraq or Afghanistan will return with PTSD/depression and/or TBI. While the VHA provides services for injured

veterans, they can be fragmented and difficult for a veteran with PTSD or TBI to engage in without the assistance of an appropriate caregiver (Griffin et al., 2012).

The United States Department of Veterans Affairs (USDVA) National PTSD Center (2007) defines PTSD as a reaction to a traumatic event, such as combat exposure. A veteran with PTSD may experience nightmares, flashbacks, hyperarousal, hypervigilance, and an avoidance of crowded places or situations that trigger memories of the trauma. According to the USDVA Polytrauma Center (2007), a traumatic brain injury (TBI) is usually caused by a significant blow to the head. A veteran with TBI could present with physical changes such as fractures, auditory, speech, and visual impairments; behavioral changes including impulsivity, regression, anger, aggression, frustration, depression, and anxiousness; and cognitive changes which include difficulty concentrating, forgetfulness, poor judgment, and communication difficulties (USDVA Polytrauma Center, 2007).

A TBI is classified in five categories according to the DOD and these include: mild, moderate, severe, penetrating, and unclassified. About 83% of US forces that are injured are classified within the mild range and are formally diagnosed when a person experiences the following symptoms: confusion or disorientation for less than 24 hours; a loss of consciousness lasting less than 30 minutes; memory loss lasting up to 24 hours; and brain imaging showing no signs of impairment (DOD, 2013).

Engaging in services can also be difficult because the Veterans Benefits Administration (VBA) has a backlog of cases from the returning veterans, which is expected to increase with the influx of returning soldiers. These claims are supposed to be processed within 125 days, per VBA regulation, but the Monday Morning Workload

Report (MMWR) published by the VBA (July 9, 2016), indicates that there are 376,573 pending compensation entitlements and 78,577 pending veterans ratings that are over 125 days (USDVA, 2016). Caregivers are critical in stabilizing the veteran while they await their ratings and compensations.

Dual diagnoses

Studies have shown that veterans who have mild TBI's (mTBI) and PTSD together can have even further impaired cognitive responses and symptoms of depression, anxiety, irritability, periods of extreme sadness, and anger than veterans with one condition alone (Kennedy et al., 2007; Levin, 2008; Macera, Aralis, MacGregor, Rauh, & Galarneau, 2012; Ragsdale, Neer, Beidel, Frueh, & Stout, 2013). Levin (2008) found that veterans tend to have less cognitive capabilities when they have both a mTBI and PTSD and this leads to exaggerated PTSD responses (Levin, 2008; Macera et al., 2012). Levin also suggests that neurologically, the system that regulates anxiety in the brain can be impacted by the presence of both a TBI and PTSD and this will limit the veteran's ability to regulate their own fear reaction. Ragsdales et al. (2013) completed a comparison study between OIF and OEF veterans with PTSD and mTBI and those with PTSD alone and the results demonstrated those with the dual diagnoses had diminished functional capabilities, more intense PTSD symptomology, and increased anxiety. Macera et al. (2012) studied longitudinally symptomatology of post 9/11 veterans who were dually diagnosed and their study indicated a latent presentation of worsening symptoms. One implication of this finding is that immediately following deployment, symptom severity may not be apparent to those working with and treating veterans. Having one condition

is debilitating, but having both can produce complicated symptoms, which makes caregiving more challenging.

Many people are unaware of the impact combat has on veterans' driving skills and why a caregiver is needed to transport them or be with them when they go places. A recent study explored Iraq/Afghanistan combat veterans with TBI and/or PTSD driving concerns and found that 93% of 205 veterans reported a deficit in one domain of driving (Lew et al., 2011). The domains included aggression/anger, lapses in concentration, driving as if in a war zone (i.e. driving through toll booths, seeing threats that do not exist, fear of bridges and pedestrians), hypervigilance, navigation problems, anxiety, flashbacks, not driving, physical/sensory problems, and other issues. The study also found that veterans with PTSD or both PTSD and TBI, exhibited more persistent problems with driving that could last years after they returned home from war zones (Lew et al., 2011). A small study (n = 20), based on Iraq/Afghanistan combat veterans in North Florida/ South Georgia, found that veterans with TBI and PTSD were more likely to experience driving errors compared to a control group of healthy civilian participants (Classen et al., 2011). These studies suggest the need for caregivers to assist veterans with reintegration.

Sayer et al. (2010) completed surveys with 754 Iraq/Afghanistan veterans to understand their needs and concerns with reintegration. Most (96%) asked for assistance from the VHA with reintegration not through traditional modalities (i.e. clinic appointments) but rather preferred methods of intervention being provided through the mail or online. Approximately 43% of the sample was likely to have been suffering from PTSD. About 25%-56% of veterans reported "some" to "extreme" concerns with self-

care, socialization, being active in the community, and being productive. Another 33% reported impairment with driving, getting divorced, increased rage, and increased substance misuse/abuse. This study emphasizes the need for caregivers of veterans to get more information and assistance with reintegration through non-traditional modalities.

Initially many family members are unaware of or unsure how these invisible injuries have impacted the veteran, but as time progresses, symptoms begin to surface and the veteran can no longer conceal them. Veterans tend to hide these injuries due to the stigma associated with them. The Office of the Surgeon Multi-National Force-Iraq and Office of the Surgeon General United State Army Medical Command. Mental Health Advisory Team (2008) found that 59% of Army personnel and 48% of Marines were concerned that their superiors would discriminate against them if they were diagnosed with PTSD or other mental health conditions and therefore concealed their illness. Milliken, Auchterlonie, and Hogue (2007) suggest that while the stigma associated with mental health concerns can dissuade a veteran from seeking assistance, the spouse may be instrumental in seeking out services for the veteran. Even though specific statistics are not available, some researchers have suggested that Iraq war veterans with TBI and PTSD are at an even greater risk for committing suicide given co-morbid psychiatric conditions such as PTSD (Harben, 2006; Jakupcak & Varra, 2011). Prior research has suggested that being married can be a protective factor against suicide with veterans (Jakupcak et al., 2010; Thoresen, Mehlum, Rosamb, & Tonnessen, 2006); thus it is essential that services are designed to keep couples together.

Vietnam veteran caregiver studies

Given the limited literature about post 9/11 caregivers, a literature review was conducted on other era veteran caregivers, but this literature was limited as well. The following summarizes Vietnam veteran caregiver studies, but these studies were also small in number (Beckham et al., 1996; Hayes et al., 2010). Some of these Vietnam veteran studies were completed with spousal caregivers of Vietnam veterans. One such study reported that partners of veterans with PTSD experienced higher levels of caregiver strain/stress when compared with veterans without PTSD and they also experienced lower levels of psychological adjustment in this study. Caregiver burden was found to be a predictor of the veteran's psychological adjustment (Beckham et al., 1996; Calhoun, Beckham & Bosworth, 2002) which illustrates the need to keep caregiver burden low in order to increase the veteran's health.

It is interesting to note that in these studies, the caregiver's available support and socioeconomic status, demographic characteristics such as race, age, and education did not have a moderating effect on the level of caregiver burden experienced by the caregiver (Beckham et al., 1996; Calhoun et al., 2002). Findings on social support are unexpected because most caregiver burden studies with the elderly and those with chronic illness found social support having a buffering effect on caregiver burden (Cohen & Wills, 1985; Zarit & Zarit, 2007). Calhoun et al. (2002) suggest that Vietnam veterans with PTSD may be socially isolated as a result of the caregivers' and the veterans' inability to access support appropriately. Veterans tend to isolate themselves when they suffer from PTSD and in particular, male veterans tend to rely solely on their wives for support and assistance when they suffer from PTSD. Calhoun et al. (2002) also included

interpersonal violence in their study and found a significant association between caregiver burden and interpersonal violence. This was one of the few studies that differentiated interpersonal violence from PTSD symptoms. Implications from this study include an additional focus on anger management in PTSD treatment.

A longitudinal study was conducted with Vietnam veterans and their spouses and caregiver burden was measured over an eight month interval while the majority of the veterans were in PTSD treatment (Beckham et al., 1996). This study found no change in caregiver burden over time despite the PTSD treatment, in fact caregiver burden increased over time. The study found a significant positive association between caregiver burden and severity of PTSD symptoms (Beckham et al., 1996). This study finding was validated by the findings in the study by Calhoun et al. (2002).

Overall it is clear that veteran caregivers' experiences are distinct from non-veteran caregivers' experiences. For veterans' caregivers, demographic characteristics and PTSD treatment did not have an effect on caregiver burden. Social support which has been a protective factor in caregivers for geriatric populations, was in essence neutralized possibly due to the symptomology of PTSD and the way it manifests which further isolates the caregiver. Therefore, exploring how the veteran's PTSD and other characteristics affects the caregiver and how they utilize support should be investigated.

Purpose of the Study and Problem Statement

Currently, the Caregiver Support Program offers caregivers a stipend, medical coverage, and mental health care through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA) and through the VHA. While these services are important, understanding this population requires research including how

veterans' "invisible" injuries and other demographics correlate with caregiver burden/stress because this is a new population of caregivers and prior research is scant. The purpose of the dissertation is to explore how demographic characteristics, having children, stipend/tier levels, and diagnoses impact levels of caregiver burden and to explore caregivers' perceptions about caregiver burden for caregivers of veterans enrolled in the Caregiver Support Program (CSP) within North Florida and South Georgia. The study uses mixed methods including a secondary quantitative analysis of recorded data with 172 participants in the program and in-depth qualitative interviews with 16 participants within this population that will explore caregivers' lived experiences of caring for a seriously injured veteran. Themes will be created from the in-depth interviews with special attention being paid to how children impact caregiving, how social media impacts caregiving, and how parents versus spousal caregivers experience caregiving.

Research Questions and Hypotheses

Quantitative research questions

1. What are the predictors of caregiver strain?
2. What are the relationships of demographic characteristics (e.g., race, age, gender) to caregiver strain?
3. How do parent caregivers differ from spousal caregivers when comparing caregiver strain?
4. Are there differences in the predictors of caregiver strain between caregivers with children and those without children?

5. How does diagnosis (TBI, PTSD, or both) affect caregivers' levels of strain?
6. What is the relationship between tier levels (higher level equals higher level of care) and caregiver strain?

Quantitative hypotheses

Hypothesis a: With respect to demographic characteristics, men would have lower levels of caregiver strain. Men view caregiving more as a task (Zarit & Zarit 2007) and experience lower levels of caregiver strain when compared to female caregivers who are scrutinized more closely by others, tend to invest emotionally, and experience higher levels of strain (Gordon & Perrone, 2004; Krammer & Thompson, 2005; Zarit & Zarit, 2007).

Hypothesis b: Spousal caregivers will have higher levels of caregiver strains than parental caregivers. Spousal caregivers tend to experience higher levels of caregiver strain and they underutilize services and resources because they feel they are better equipped to provide care than other agencies and services (Zarit & Zarit, 2007). Spouses also tend to experience higher levels of psychological strain (Gordon & Perrone, 2004; Verhaeghe, Defloor, & Grypdonck, 2005).

Hypothesis c: Caregivers with children in the home would have higher levels of caregiver strain than those without children in the home. Even though there are no published studies that explore how children are impacted when a parent is injured in Iraq/Afghanistan, Pemberton, Kramer, Borrego, & Owen (2013) speculate based on research in other areas that children will have emotional and behavioral disturbances. Increased behavioral issues in children may contribute to increased caregiver burden.

Hypothesis d: Caregivers caring for veterans with dual diagnoses would have higher levels of strain than those caring for veterans with a TBI or PTSD alone. Studies have shown that veterans who have mTBI's and PTSD together can have even further impaired cognitive responses and symptoms of depression, anxiety, irritability, periods of extreme sadness, exaggerated PTSD responses, and more anger than with one condition alone (Kennedy et al., 2007; Levin, 2008; Macera et al., 2012; Ragsdale et al., 2013).

Hypothesis e: Caregivers being paid at the higher tier levels would have higher levels of strain. There is no literature that has explored the strain levels with caregivers that are being paid through the CSP, but since most of the caregivers that are being paid at the higher levels have veterans who were scored at higher levels of need by their providers it would be safe to assume they are performing more caregiver tasks. Caregivers who perform more caregiving tasks experience higher levels of strain (Montgomery, Gonyea, & Hooyman, 1985).

Qualitative research questions

1. What are the lived experiences of spousal and parental caregivers of veterans returning from Iraq and Afghanistan? Are there differences between the lived experiences of spouses and parents?
2. How have the caregiving experiences changed before the caregiver support program services vs. after receiving services? Are there differences between the changes for spouses and parents?
3. How does having children affect the spousal caregiving experiences?

4. What is the role of online support community (e.g., social media, blogging) in caregiving experiences? Are there differences in the role of online support between spousal caregivers and parental caregivers?

Limitations

Little is known about the caregivers of Iraq and Afghanistan veterans (Tanielian et al., 2013). Many of these soldiers are still in the process of returning to the United States, so while this dissertation study may provide some information based on a small segment of this population, it will not be an inclusive study of all caregivers of Iraq and Afghanistan veterans. This dissertation study also is limited to caregivers that reside in the North Florida /South Georgia Veterans service area that are enrolled in the Caregiver Support Program (VISN 8/ VA 573). It is estimated that over 900,000 veterans are returning from Iraq and Afghanistan, but only 45% are utilizing VHA services (Jakupcak & Varra, 2011), so there are many informal caregivers in the community that are not being sampled in this study. This study only includes caregivers of veterans with serious injuries such as PTSD and TBI. This means that the study is limited to veterans with a service connected disability, i.e. an injury that was incurred while in service. The veterans should be receiving financial compensation for these injuries as well as the caregivers for providing care; therefore, the true impact of the financial burden of caregiving may be minimized by the increased income from the Caregiver Support Program.

Significance of the Study

This is the first study that examines caregiver strain amongst Iraq and Afghanistan veteran caregivers. Quantitative data have already been gathered since the inception of

the Caregiver Support Program, but an analysis has yet to be completed. This study is also the first study to explore how this federally funded program has impacted caregivers in terms of caregiver strain as well as support services. Family caregivers have in essence saved millions of dollars in the cost of care by providing these services in their homes, rather than in institutions (Tanielian et al., 2013; Ramchand et al., 2014) and this is one of the first programs that aim to reduce the strains associated with caregiving including financial burden, mental health impacts, and physical health problems. This study also seeks to understand the distinct characteristics of this population of caregivers as they are much younger than most NMCG's, some with young children and are so technologically connected.

Definitions

See Appendix A

CHAPTER 2: LITERATURE REVIEW

Chapter 2 provides a theoretical framework that explains the transition an individual or family makes once a loved one is injured or they assume the role of a caregiver. Lazarus and Folkman's (1984) stress and coping theory in conjunction with the stress process model and life course theory (Hutchison, 2011; Pearlin, 2010) have been used as the conceptual framework throughout this study. The framework is applied to the current population of study and explores the limitations based on previous studies. This is followed by a literature review on all the variables that are the focus of this study with a summation of current studies as well as past studies that have been used to inform this study.

Theoretical Overview

Theories can be described as an organized set of ideas and statements based on facts and observations that are used to explain a phenomenon (Barker, 2003; Payne, 2005). For the purposes of this study, Lazarus and Folkman's (1984) stress and coping theory provides a foundation to gain an understanding of the caregivers' internal processes that lead to their successful adaptation to their new role or to caregiver burden. This theory is further expanded by the works of Hutchison (2011), Pearlin et al. (1990), and Cohen and Wills (1985) to describe how changes in the life course and mediating variables such as social support and internal coping mechanisms can affect the caregivers stress levels as well as how a caregiver adjusts to their new role.

Stress and Coping Theory

Stress and coping theory was developed by Lazarus in the early 1950's and has been further elaborated by other researchers. Many different fields define stress according to their area of research, but according to Lazarus (1966) stress should not be seen as one variable, but as a construct that may be chronic or acute and composed of many factors and processes with individualistic responses. Lazarus and Folkman (1984) use the definition of psychological stress defined as “the 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 wellbeing” (p. 21). Figure 2.1 represents the stress and coping model and explains the processes an individual goes through once presented with a stressor, which in this case can be the veteran's injury or the act of caregiving.

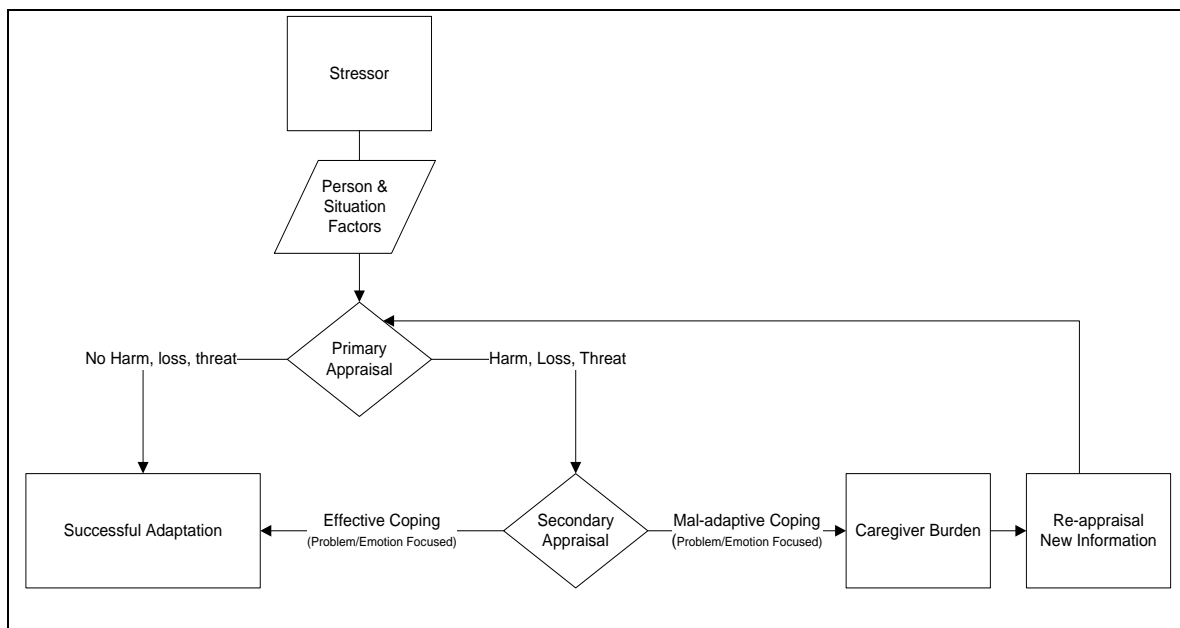


Figure 2.1: The stress and coping model. Adapted from Stress and Coping Theory (Haley, Levine, Brown, & Bartolucci, 1987; Lazarus & Folkman, 1984).

Appraisal phase

Once a stressor presents itself, an individual/caregiver usually goes through an appraisal phase which consists of primary, secondary and reappraisal phases. In the primary phase the caregiver will decide if the stressor causes no harm, is positive, or is stressful. If it is stressful the caregiver will decide if it is a harm/loss (something the individual has already experienced), a threat (potential) or a challenge (something that can be mastered). During the secondary appraisal, the individual will explore their options such as coping mechanisms or strategies and their consequences and implementation. Lastly, during reappraisal, the individual will, if indicated, reevaluate the previous appraisal based on some form of new information (Haley et al., 1987; Lazarus & Folkman, 1984).

Person factors and situational factors

There are many factors that can affect the individual's cognitive appraisal of the stressors. These factors include person factors such as commitments and beliefs, and situational factors such as: the novelty and predictability of the stressor, the event uncertainty, temporal factors, ambiguity, and the timing of the event. Vulnerability is also a factor that convolutes the situation and is identified as a person with maladaptive coping or lacking coping resources (Carretero et al., 2009; Haley et al., 1987; Lazarus & Folkman, 1984)

Coping mechanisms

Once a person has appraised the stressful event, they can utilize coping mechanisms. Coping mechanisms adapt and change with the situation and can be based on previous attempts of coping (Lazarus & Folkman, 1984; Pearlin et al., 1990). Coping

is a deliberate action/behavior that is used to get through the stress of caregiving whereas a defense typically results from a failed attempt to cope (Lazarus & Folkman, 1984).

There are two functions that coping serves; emotion-focused coping where ones tries to control their emotional responses and problem-focused coping where one will try to control and change the environment within which the stress occurs (Carretero et al., 2009; Haley et al., 1987; Lazarus & Folkman, 1984).

Adaptation

The final stage known as adaption, examines how the caregiver is impacted by the stressor in the short and long terms. The three areas in which adaptation occurs include: social functioning, morale, and somatic health. Social functioning is viewed as an individual's roles, which encompass work and social roles. Morale is a multidimensional construct which can be measured using the quality of life index or a life satisfaction index and somatic health contains both physical and psychological health (Clay et al., 2013; Haley et al., 1987; Lazarus & Folkman, 1984). Of note, chronic stress, such as one experiences in caregiving, can result in adverse physical and mental health consequences (Cohen & Wills, 1985) if one does not take the time to self-care, or utilize effective coping mechanisms (Lazarus & Folkman, 1984).

One of the limitations of the stress and coping theory includes the lack of social support which is seen in the literature as "buffering" the caregiver from experiencing burden and life course changes which include timing, sequence and mastery. Current literature adds these concepts as factors that impact a caregiver's adaptation to their new role (Cohen & Wills, 1985; Pearlin, 2010; Zarit & Zarit, 2007). For this study, social

support is being added to the theoretical framework in order to capture this protective factor.

The Stress Process Model and Life Course Theory

Pearlin (2010) reviewed his previous work with the stress process model and effectively combined this model with some of the key components of life course theory. The stress process model with life course theory can be used to explain the adjustment the caregiver makes when they are placed in the role of caregiver and how that can result in caregiver burden if coping strategies such as social support and coping mechanisms are not adequate (Lazarus & Folkman, 1984; Pearlin, 2010; Pearlin et al., 1990).

According to Pearlin et al. (1990), the stress process model consists of four domains including the history and circumstances surrounding the stress, the actual stressor, mediating factors, and the effect of stress, which in this case is the caregiver stress outcomes. For example, when a caregiver is exposed to stress (i.e. caregiver tasks or change of role from spouse to caregiver), their coping skills and coping strategies, including social support, act as mediating factors that buffers them from caregiver stress (Clay et al., 1987; Cohen & Wills, 1985; Pearlin, 2010; Zarit & Zarit, 2007). But when a caregiver is void of resources, vulnerable, or already has maladaptive coping skills, this can be problematic and the end result is caregiver strain or burden (Cohen & Wills, 1985; Pearlin, 2010; Wheaton, 1985; Zarit & Zarit, 2007).

Contextual factors

As with the stress and coping model, historical and contextual factors play an important role in determining how an individual will respond to stressors, what mediating factors they will utilize, and what the outcome to the stressor will be. Contextual factors

include demographic information, caregiving history, socioeconomic information, the veterans' demographic information, injury type, social support, and coping mechanisms of the caregiver (Lazarus & Folkman, 1984; Pearlin, 2010; Pearlin et al., 1990; Zarit & Zarit, 2007). All of these factors in combination can help in identifying caregivers that may be at a higher risk of experiencing caregiver burden.

Life course factors

The life course perspective can be described as a process that examines transitions such as age, relationships, life transitions, and social changes and how they mold and change individuals throughout their lifespan (Hutchison, 2011; Pearlin, 2010). Figure 2.2 represents the theoretical model being used in this study and demonstrates how the stress process model and life course theory interact with mediating variables and result in the caregivers stress outcome.

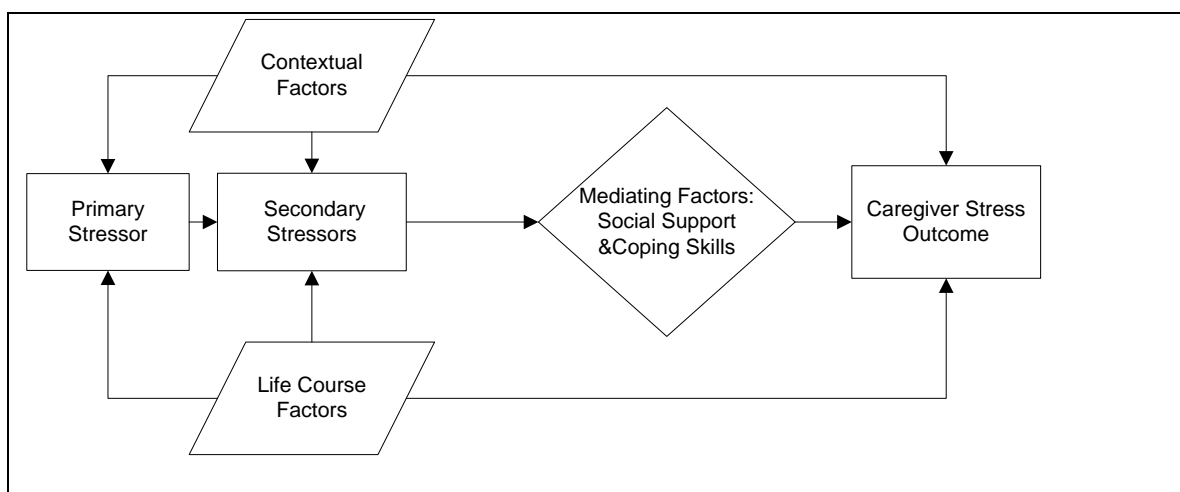


Figure 2.2: Represents the stress process adapted with life course theory (Pearlin, 2010; Pearlin et al., 1990).

In Pearlin's works, he described how stress manifests within the life course. He refers to timing, sequence, transitions, agents, and mastery which are core concepts in life

course theory and how they interplay with the Stress Process model. This is even more evident with the role of a caregiver since the timing and sequence of this transition is typically unexpected (Pearlin, 2010).

In addition, Pearlin found that normal or expected transitions in life typically result in less stress than transitions which were not anticipated. He speculates that preparation and anticipation (i.e. situation factors) of these events may be the reason why an individual is able to work through these transitions. Sometimes, however, even with anticipation, the transition can create considerable stress unless the individual possesses adequate coping mechanisms and social support (Lazarus & Folkman, 1984; Pearlin, 2010).

Primary and secondary stressors

In this study, with the unexpected transition of having to provide care for the returning veteran, the life course trajectory changes. The caregiver experiences a primary stressor, which in this case would be the “invisible” injury sustained by the veteran and/or the realization that they must provide care for this individual, and as a result secondary stress presents itself. This secondary stress can take many forms such as problems sustaining employment while providing care, health and psychological consequences, or having to be up at night while a veteran suffers a nightmare or flashbacks. These secondary stressors typically include constructs related to caregiver burden such as role strain or personal strain (Pearlin, 2010; Zarit & Zarit, 2007).

Mediating variables

In the caregiving literature, three factors emerge as protective factors against caregiver strain including social support, caregiver resources, and coping mechanisms

(Pearlin, 2010; Savundranayagam & Montgomery, 2010; Zarit & Zarit, 2007). Together, social support including actual support and perceived support (Monahan & Hooker, 1997), coping mechanisms such as coping traits and styles (Lazarus & Folkman, 1984), and coping strategies/resources such as respite, financial relief, and self-care (Dow & McDonald, 2003; Monahan & Hooker, 1997; Pearlin, 2010; Savundranayagam & Montgomery, 2010; Zarit & Zarit, 2007) act as mediating variables that help to determine the extent to which a caregiver successfully adapts to their new role or not.

The stress process model suggests that those with social support will react better to the situation of caregiving, but a study with Iraq and Afghanistan veterans suffering from PTSD indicated that this was not the case (Jakupcak et al., 2010). Ray and Vanstone (2009) also corroborated this experience in their study of Canadian servicemen with PTSD. While social support was important for the caregivers, the veterans' maladaptive behaviors led them to lose social support and become even further isolated. Jordan et al. (1992) also found that wives of Vietnam veterans with PTSD had some fulfillment and joy when they implemented their own coping mechanisms when dealing with the stressors of caring for veterans with PTSD. The authors suggested that it was intrinsic coping mechanisms and not resources or social support that resulted in the relationship remaining intact. No studies have been published that address stress and coping theory with veterans with TBI, but these studies with veterans with PTSD may provide insight into the processes to be aware of when exploring this theory with caregivers.

Overall the stress process model, stress and coping theory, and life course theory provide us with a portrait of the issues caregivers face when they are faced with an

unexpected transition such as caregiving and what factors explain negative and positive adjustments these caregivers make. Applying the final model to the population of study helps to explain what variables contribute to a successful transition into caregiving and/or result in caregiver strain/stress. It is important to remember, however, that most of these studies have been conducted on older adults with cognitive deficits (Dow & McDonald, 2003). Whether the same factors are relevant to this new population of caregivers remains to be explored. Based on the limited research with this new population, it appears that social support, especially in cases of PTSD, may not be as effective in reducing caregiver's burden, but rather the internal coping mechanisms caregivers possess or develop are critical (Jakupcak et al., 2010; Jordan et al., 1992; Ramchand et al., 2014; Ray & Vanstone, 2009).

Variables of Study

Demographics and caregiving

Since September 11, 2001 (9/11), there have been over two million troops deployed of which 55% are married and 40% with children (Flake, Davis, Johnson, & Middleton, 2009). Current estimates report that there are approximately 1.1 million post 9/11 military caregivers, the majority (49%) of which are between the ages of 31-55 (Ramchand et al., 2014), with a mean age of 38 (Tanielian et al., 2013). Previously collected data on military caregivers reported that the majority of post 9/11 caregivers were females, (NAC, 2010; Tanielian et al., 2013), however a recent study reports that in actuality, 40% of post 9/11 caregivers are males (Ramchand et al., 2014). The authors cite convenience sampling a barrier to acquiring accurate numbers in previous studies. Of these caregivers, 33% are spouses, 25% are parents, 6% are children, 10% are other

family members, and 23% are friends (Ramchand et al., 2014). Of the spouses, approximately 76% of them are working (Ramchand et al., 2014) with over 84% having some form of college education, 25% with a bachelor's degree and about 10% with higher level degrees (USA, 2011). One of the unique attributes of this group of caregivers are that 43% are of non-white race/ethnicity and 20% have also served in the armed forces (Ramchand et al., 2014). There are approximately 20% of post 9/11 caregivers caring for a veteran with a TBI and 54% who are caring for a veteran with PTSD (Ramchand et al., 2014). It is also estimated that 39% of post 9/11 caregivers also care for a child under the age of 18 (Ramchand et al., 2014).

Gender

According to Ramchand et al., (2014), 40% of post 9/11 caregivers are male. They are unique when compared to their female counterparts in that 50% are caring for a friend/neighbor versus 51% of females who care for their spouses. The person that they are providing care for tends to be unmarried (44%) which is significantly higher when compared to female caregivers (29%). Less than half (46%) spend more than eight hours a week providing care, whereas approximately 71% of females spend over 8 hours a week providing care. Men also are performing less caregiving tasks, with significantly less when it comes to instrumental activities of daily living (IADL's). The care recipient is also not as likely to have a mental illness and about one fourth of these male caregivers have served in the military (Ramchand et al., 2014).

Since in-depth research on caregivers of veterans is limited, evidence based on other caregiver populations may help understand why caregiving experiences could differ depending on demographic characteristics of caregivers. The gender of the caregiver has

been studied and male caregivers tend to have lower levels of caregiver stress and strain compared to female caregivers (Krammer & Thompson, 2005; Zarit & Zarit, 2007), however this may be a result of underreporting by males (Lutzky & Knight, 1994). Gordon and Perrone (2004) found that women felt less prepared to cope with the strains of caregiving and received increased levels of scrutiny from others when they provided care (Pearlin, 2010). Men saw caregiving more as a concrete task, whereas women invested their emotions into caregiving which resulted in increased caregiver strain (Zarit & Zarit, 2007). Kramer and Thompson (2005) suggest that being a male caregiver may have a moderating effect on caregiver strain. Therefore, it is likely women will encounter increased levels of caregiver burden (Lee, Walker, & Shoup, 2001; Zarit & Zarit, 2007).

Race

Racial and ethnic differences have been studied in caregivers for individuals with brain injuries and other injuries. Studies indicate that there are no differences across races when comparing caregiver burden of individuals who are caring for someone with a TBI (Nabors, Seacat, & Rosenthal, 2002; Sander et al., 2007). African American caregivers tended to be less educated, but more likely to provide care to other family members and children when compared to whites who typically cared for spouses, and more likely to feel their needs were not being met (Nabors et al., 2002). Even though Hispanics and African Americans felt more acceptance in their role as a caregivers and utilized emotion focused coping more effectively compared to whites, it still resulted in no difference in emotional distress across races (Sander et al., 2007).

Spousal Caregivers versus Parental Caregivers

There is an abundance of research that focuses on adult children caring for a parent or older spouses caring for one another, but research is limited on caregiving with younger couples, when one partner suffers a chronic illness (Tanielian et al., 2011). Spousal caregivers tend to have increased levels of psychological strain when compared to other caregivers such as parental caregivers and adult children caring for their parents with a disability (Gordon & Perrone, 2004; Verhaeghe, Defloor, & Grypdonck, 2005). It seems that spouses tend to invest more of themselves when providing care and therefore tend to suffer more consequences such as financial burden, physical and psychological ailments (Pinquart & Sorensen, 2011). Anderson et al. (2009) examined how family functioning and psychological strain were affected when comparing parents and spouses caring for someone with a TBI. The results were mixed, but behavioral problems and cognitive deficits were the key contributors to spousal distress whereas only cognitive deficits were the main causes of strain and family disruption with parent caregivers. The caregivers also tend to receive less social support from others when they were providing care to their spouses (Young & Grundy, 2008). Based on recent findings, Iraq and Afghanistan spousal caregivers face more complicated issues and are providing care at younger ages for longer periods of time, with a limited or sometimes non-existent support network (Ramchand et al., 2014; Tanielian et al., 2011). They are also experiencing increased psychological and physical consequences when compared with pre 9/11 and civilian caregivers (Ramchand et al., 2014). Therefore, spousal caregivers are at risk of experiencing increased strain and burden.

Socioeconomic Factors and Caregiving

There is a paucity of data about informal caregivers who are in the workforce and providing care in the community (Borg & Hallberg, 2006; Griffin et al., 2012). Veteran caregivers are no exception. In fact, there is even less research that provides information about how caregiving impacts employment or the effects of financial strain for caregivers of veterans with serious injuries (Griffin et al., 2012).

Veteran caregivers (VCG) tend to experience even more financial strain (Griffin et al., 2012) and caregiver burden (Borg & Hallberg, 2006) compared with elderly caregivers since VCGs typically tend to be younger (Griffin et al., 2012), and are juggling family life and employment (Borg & Hallberg, 2006) which can result in lifelong financial consequences for younger caregivers (Griffin et al., 2012). Even though employment can be a protective factor against caregiver burden, once the care being provided becomes more involved, this protection diminishes (Lee et al. 2001).

The Families and Caregivers Experiences Survey (FACES), one of the first studies with Iraq/Afghanistan VCG, explores caregivers leaving their jobs and how debt accumulation and use of assets can be a method of coping for these new VCG (Griffin et al., 2012). The survey explored VCG financial history, employment status, debt, and expenses associated with caregiving. The sample surveyed included caregivers of veterans who were seriously injured and suffered polytrauma, which includes TBI in combination with other injuries, including PTSD. These veterans were treated at one of the nation's four polytrauma centers that provide comprehensive rehabilitation for these individuals. The caregivers tended to be Caucasian females, with some college education and annual incomes that ranged from \$50,000 to \$80,000 the year before they became a

caregiver. There were more parents as caregivers (62%) with their median age being 54 than spouses/partners (32%) with their median age being 34 (Griffin et al., 2012).

The results clearly indicate the struggles post 9/11 VCG experience with 62% of VCG using all of their assets and acquiring debt in order to provide/pay for care and 41% leaving their place of employment. On average caregivers with veterans with higher levels of care needs (both ADL and IADL) were in debt \$27,576 versus \$15,540 for veterans with moderate needs. Male caregivers had about \$9,000 more debt than female counterparts, and those who cared for the veteran from the date of injury gathered on average \$14,762 more debt than those who came into the picture as a caregiver at a later time. The overall finding suggested that gender, veteran's level of care when discharged, current care needs, and the caregiver providing care from the time of injury as significant predictors of use of assets and accumulating debt (Griffin et al., 2012).

VCG respondents to the survey left the workforce in high numbers based on level of care (Griffin et al., 2012) even though employment has been associated with lower burned scores and a necessity for financial security (Borg & Hallberg, 2006). Veterans with greater care needs resulted in a five times increase in odds of the caregivers leaving their job versus two times increase in odds for those with moderate care needs. Men and those with higher levels of income were less likely to leave their jobs; those who were older and with higher education levels were more likely to leave (Griffin et al., 2012).

Post 9/11 caregivers indicated that they have a higher financial burden than other VCG's and they miss on average a full day worth of work per a week more than non-caregivers (Ramchand et al., 2014). This is even further compounded by the 42% salary differential between military and civilian females working similar jobs (USA, 2011).

Another survey administered by DOD found that military families reported their number two stressor as being financial management (USA, 2011). When compared to numbers in other caregiver populations, it appears the VCG pay a much higher price considering these caregivers tend to be younger and dealing with more complex issues (Tanielian et al., 2013). How this impacts VCG's and their families longitudinally is unknown. It could potentially impact savings, retirement, and meeting their children's educational needs. Veterans who are injured receive financial benefits from the VBA, but caregivers do not (Griffin et al., 2012).

One of the important aspects of the Veterans and Caregivers Omnibus Act is that caregivers can receive a stipend while remaining employed. Given that employment can be seen as a protective factor against caregiver burden (Borg & Hallberg, 2006), the legislation clearly values the importance of minimizing role strain on the caregiver by eliminating the need to choose between employment and caregiving which can provide a sense of purpose and relief from the day to day task of caregiving.

Caregiver Burden Associated with Caring for a person with a TBI

TBI's are not a new concept when it comes to caregiving. Caregivers have been providing care to individuals with brain injuries for years. Many of these brain injuries can result from accidents and strokes and there is literature related to caregiver burden in caring for victims of brain injury, but the literature is sparse on caregivers of veterans who have sustained a TBI (Griffin et al. 2009).

Caregivers who are caring for individuals with TBI reported being unsatisfied with their life up to two years after their family member was injured. The caregiver's life satisfaction was also compared to adults with no caregiving responsibilities and results

also demonstrated lower life satisfaction (Livingston et al., 2010). Suicide risks for veterans with TBI are 1.5 times higher than those of veterans without TBI (Brenner, Ignacio, & Blow, 2011) and veterans in general tend to have a significantly higher risk of suicide when compared to the general population (Kang et al., 2015). These statistics alone demonstrate the need for a caregiver to help regulate veterans and keep them safe during re-integration.

Anderson et al. (2009) found that parental caregivers fared much better in terms of psychological distress and family functioning compared to spousal caregivers when their loved ones diagnosed with TBI presented with behavioral problems. The only exception was that when cognitive deficits were involved with the care recipient, parents tended to experience much distress and family disruption compared to spouses.

Verhaeghe et al. (2005) completed a literature review that focused on studies that documented psychological reactions of family members caring for individuals diagnosed with a TBI and they found that spouses and children tended to be the most susceptible to stress and family strain, particularly those who are already suffering from financial burden and impaired health. Younger families were also vulnerable to negative impacts. The authors suggested that care teams pay particular attention to their interactions with the patients and families so as to not add additional strain to already impaired family systems. In addition, they found a positive correlation between the patient's recovery and family functioning (Verhaeghe et al., 2005).

Overall, it appears that caregivers are essential in the recovery of persons with TBI. Careful focus should be placed on spousal caregivers with children who are younger (Verhaeghe et al., 2005) which tends to describe the population of veteran

caregivers from the Iraq and Afghanistan wars. Lastly, it is important to understand the stressors these families are already experiencing and care teams should be a source of support, not conflict, for these already vulnerable populations.

Caregiver Burden in Veterans with PTSD and or TBI

Literature on caregivers of Iraq and Afghanistan veterans suffering from PTSD and TBI is limited. The following represents the sparse literature specific to caregivers who care for a veteran with PTSD and/or TBI. During the Second Annual Trauma Spectrum Disorder Conference that was held in 2009, one of the identifiable gaps in research presented at the conference was the need for in-depth research on veterans with Trauma Spectrum disorders (O'Donnell, Begg, Lipson, & Elvander, 2011; Tanielian et al., 2013). Given these are the “signature” injuries of these current wars, it is important to have an understanding of the stress their caregivers face. A common theme with caregivers is that the loved one that has returned from combat has changed drastically and most caregivers are unprepared or unwilling to hear about the psychological impact of warfare on the veteran, not to mention the stigma that is associated with such disorders (O'Donnell et al., 2011).

Phelan et al. (2011) found that there are different types of stigma associated with veterans who have TBI and their caregivers. The authors sought to differentiate which type of stigma had the most impact on caregiver burden rather than just grouping stigma into one category. The results demonstrated that perceptions of being discriminated against and the stigma associated with being a caregiver were significantly associated with depression, anxiety, isolation and caregiver strain (i.e. mental health outcomes). The need to conceal the veteran's condition was associated with isolation from others,

strain, and a higher rate of depression. Rabin and Nardi (1991) found this with combat veteran's spouses in Lebanon who suffered from PTSD. The couples were socially isolated from available supports and very guarded (Rabin & Nardi, 1991) which has also been reported with post 9/11 caregivers (Ramchand et al., 2014). Social isolation can be exacerbated further as veterans often enter the military because of troubled relationships with their families and once they leave the military with a mental health diagnosis these relationships tend to deteriorate further (Hayes et al., 2010). The implications are that further exploration into the type of stigma caregivers experience is warranted as some forms of stigma have a greater impact on caregiver burden than others, particularly when it comes to social support.

Hayes et al. (2010) completed a study to identify the domains specific to caregiver burden that caregivers of Iraq and Afghanistan veterans experience based on two focus groups: one with experts in the field and the other with seven wives of veterans from this population. Their findings include: physical and mental health, alcohol and other substance abuse, quality of life, suicide specific to females in this population, coping and social support as supported by the stress buffering model, domestic violence, spouse burden, reversal of roles, satisfaction with marriage, the parent and child relationship, and conflicts. One of the areas that the wives tend to not report as problematic is alcohol abuse by their spouses (Hayes et al., 2010; Jordan et al., 1992; Milliken et al., 2007) which contradicts what experts identified as a domain with veteran populations (Hayes et al., 2010) as well as what veterans themselves have reported as an issue (Jordan et al., 1992; Milliken et al., 2007).

Lambert, Engh, Hasbun, and Holzer (2012) completed a meta-analysis on civilian couples and military couples including military participants from Iraq/Afghanistan and Vietnam who suffered from PTSD. They found that PTSD had damaging effects on their partners with a larger effect size on women partners of veterans with PTSD versus male partners. Veterans with PTSD presented with higher associations between PTSD and relationship dispute with their spouses and aggressive behaviors when compared to non-military populations leading to speculation that the military culture and their exposure to combat may influence and even reinforce the behavior resulting in a higher risk of intimate partner violence (Taft, Watkins, Stafford, Street, & Monson, 2011). The veteran's military involvement has also been found to be a moderator between PTSD and relationship satisfaction (Lambert et al., 2012; Taft et al., 2011). While these studies examine the effects on partners, the effects on children have yet to be examined.

Caregiving and Children

With over 700,000 children living with a parent being deployed to this conflict, it would appear reasonable to assume some children would experience adjustment difficulties with a parent absent, but there is little literature about the impact on children and families when a parent returns injured (Pemberton et al., 2013). Boys have shown a tendency to replicate their father's disruptive behaviors (Hayes et al., 2010) which is concerning as many veterans who are returning are suffering from PTSD and have difficulty managing their anger. This can only increase the burden a caregiver experiences when trying to regulate a veteran's mood as well as shelter and regulate a child's reaction (Flake et al., 2009).

Ramchand et al. (2014) queried post 9/11 caregivers, pre 9/11 and civilian caregivers about the benefits and negative consequences caregiving has on their children and families. All three groups reported benefits ranging between 44 and 53 percent, with no negligible difference between the groups. Children have been reported to help caregivers and seen as the only trustworthy source of support for post 9/11 caregivers (Tanielian et al., 2013). With respect to negative consequences, 44% of post 9/11 caregivers felt caregiving impeded them spending quality time with children, 46% felt that caregiving created a stressful home environment, and 27% felt being a caregiver resulted in them being a worse parent. These findings were substantially different when compared with pre 9/11 and civilian caregivers, who scored lower in all three areas (Ramchand et al., 2014).

Pemberton et al. (2013) suggested a need for parenting interventions within the VHA for returning Iraq/Afghanistan veterans. The researchers suggest that even though there are no published studies that report children are impacted when a parent is disabled or injured in Iraq or Afghanistan, they speculate based on research in other areas that they will have emotional and behavioral disturbances (Pemberton et al., 2013). These caregivers will also spend more time trying to meet basic needs of everyone in the family rather than focusing on tasks that meet the developmental needs of the children (Miller, Houston, & Goodman, 1994). Other researchers have provided results that point to increased strain in caregivers when a child exhibits emotional and behavioral problems shown to contribute to caregiver strain in the parents (Baker et al., 2003; Evans, Sibley, & Serpell, 2009).

Based on the limited number of studies that have been completed, some conclusions can be drawn. Children will manifest poor psychological adjustment if the parent is experiencing stress, particularly with post 9/11 veteran caregivers (Ramchand et al., 2014). If a parent is caring for a veteran, there is likely to be some form of stress or strain, unless the parent has good coping skills and adequate social support. There is potential that a veteran with TBI or PTSD would exhibit symptoms upon their return that would only add to the child's adjustment difficulties. Since there is research to suggest that increased behavioral adjustment in children will result in increased caregiver stress and poor outcomes for veterans' adjustment (Evans, Cowlshaw, Forbes, Parslow, & Lewis, 2010), it is even more essential that services be targeted to the whole family system (Flake et al., 2009). Therefore, supporting and assisting the caregiver and children in the home would be crucial for the veteran's recovery and reciprocally for the family's improved functioning. As Pemberton et al. (2013) suggest, there is a need for the VHA to start working towards interventions aimed at improving family functioning that targets children as well.

Social Media as Social Support

The VHA has recently launched several programs aimed at providing coping resources and support to veteran caregivers that are exclusively available online. One program is Building Better Caregivers, a support community for caregivers of veterans. It is a six-week course that has been tested at Stanford University that provides support, resources, and discussion boards for caregivers. There are modules that the caregivers complete and the end result in studies indicate lowered levels of caregiver strain (Lorig et

al., 2012). Results support a significant reduction in stress when compared longitudinally at week one versus week six (Dupke, Plant, & Kosteas, 2016).

The VHA piloted an IPAD project that provides caregivers pre-loaded IPADS with caregiver resources (United States Department of Veterans Affairs, (2012). VA Mobile Health Program, 2012). On the launch pad, there are eight programs that the caregiver can access. All the data entered and used is recorded to see the versatility of the program/device. Included in the programs are the full Zarit caregiver burden scale, a journaling application for the caregiver to use, as well as a Care4Caregiver app that provides tools for caregivers to deal with the stressors involved in caregiving. The Caregiver answers a self-assessment and depending on the score certain resources and tools appear for the caregiver to use such as deep breathing and progressive muscle relaxation (VA Mobile Health, 2012).

A peer mentor program is available online where the VHA has trained peer caregivers to provide support and assistance with other caregivers via phone and via email (VA Caregiver Support Program, 2016). In addition, there are several blogs and online support communities that are being utilized by caregivers of veterans. While previous generations of caregivers were not as “connected” on line, today’s younger caregivers and veterans are and alternatives to traditional methods are suggested by current researchers (Sayer et al., 2010) as today’s veteran caregivers are juggling with multiple obligations and have limited time and flexibility (Fischer, Sherman, Han, & Owen, 2013). There are websites specific to caregivers of veterans where advice, programs, and resources are provided as listed in Table 2.1 (Patel, 2015).

Table 2.1: Online Caregiver Resources

Resource	Locator reference
Wounded Warrior Wives	www.facebook.com
Hearts of Valor	www.heartsofvalor.org
The Well Spouse Association	www.wellspouse.org
National Military Family Association	www.militaryfamily.org
Easter Seals	www.easterseals.com
National Alliance for Caregiving	www.caregiving.org
VA Caregiver Support	www.caregiver.va.gov

The VHA is collecting data on the on-line programs they have piloted; the results will help us understand whether these resources are beneficial.

Summary and Conclusion

It is clear from the literature review that information about the new generation of veteran caregivers is segmented and the issues that caregivers face are complex. Demographically, gender appears to play a role in caregiver burden based on studies from geriatric populations (Gordon & Perrone, 2004; Kramer & Thompson, 2005; Zarit & Zarit, 2007). Male caregivers view caregiving as a task and invest less emotionally than female caregivers (Zarit & Zarit, 2007). Parents also seem to suffer less from caregiver strain compared to spouses. Other demographic variables such as race, appear to have a limited effect, specifically with those caring for individuals with TBI (Nabors et al., 2002; Sander et al., 2007).

Diagnosis and behavioral issues seem to play an important role in the amount of strain that caregivers experience, particularly when a veteran suffers from PTSD or PTSD/TBI combined. While previous research has suggested that coping and social support are protective factors caregivers can engage in to lower strain (Pearlin, 2010; Zarit & Zarit, 2007), with chronic PTSD, the protective factor of social support seems to be eliminated (Fischer et al., 2013; Kaniasty & Norris, 2008; Ramchand et al., 2014). There can be many reasons for this including the nature of the disorder which causes individuals to isolate themselves, engage in avoidance, and/or experience paranoia. Along with the isolation comes other risks that result from the veteran's avoidance and emotional numbing symptoms including domestic violence, difficulties with parenting, and divorce (Fischer et al., 2013; Taft et al., 2011). Overall, it is clear that this very vulnerable population needs to be explored and once an understanding of the issues they are facing are clear, interventions and programs can be developed or improved upon.

CHAPTER 3: METHODOLOGY

Research Design

The dissertation study used an explanatory sequential mixed methods design where a quantitative study was followed by a qualitative inquiry to elaborate findings in the quantitative study (Creswell, 2009). This mixed methods design helps to develop a deeper understanding of the problem being examined rather than using one method alone (Creswell & Plano Clark, 2007). The utilization of a mixed methods study of caregiver burden is appropriate because little research has been done with this new population and there was existing quantitative data from the Caregiver Support Program has not been utilized. Quantitative methods are used when theory or parts of a theory are being tested or examined to determine a relationship between variables (Alston & Bowles, 2003; Creswell, 2009). They are also used to find the *truth* or *objective reality* whereas qualitative studies are used to gain an understanding of the meaning people give to phenomenon in question (Alston & Bowles, 2003; Creswell, 2009). For this particular study, a quantitative method was used to determine if there are relationships between variables and a phenomenological approach was used to explore this new population of caregivers and their shared lived experiences in caregiving.

Phenomenology

Creswell (2009) describes phenomenology as an approach that is focused on how the participants describe their lived experiences. Phenomenology was introduced as a

research method in the early twentieth century by Edmund Husserl. His aim was to be able to extract the meanings people attribute to certain events at particular times, but also being careful to set aside (*bracket*) our own views and perceptions about the phenomenon in question (Pringle, Hendry, & McLafferty, 2011; Willig, 2008). From the perspective of phenomenology, every person may and will experience the same phenomenon differently based on their own thoughts, views and experiences (Willig, 2008). While each caregiver may experience their own lived experience of being a caregiver, phenomenology gathers experiences from multiple caregivers in order to create a commonly shared experience of Iraq/Afghanistan veteran caregivers (Alston & Bowles, 2003; Creswell, 2007; Pringle et al, 2011). Phenomenology is exploratory in that it is trying to explore lived experiences about a phenomenon that has not been explored or understood (Laverly, 2003). In-depth interviews with participants are conducted with some requiring multiple interviews in order to gather the rich and thick descriptions which capture the “essence” of the individual’s experiences (Creswell, 2007; Moustakas, 1994). In this study, caregiver experiences within three different contexts were explored: caregiving as a spouse, caregiving as a parent, and caregiving with children in the home.

Site and population

IRB approval was obtained to complete a retroactive file review of already gathered quantitative data on all participants (180) in the Caregiver Support Program (CSP) in the North Florida/South Georgia VHA and for recruitment of up to 20 participants for the completion of the qualitative portion of the study.

All of the caregivers in this study were approved for the CSP and were caring for veterans who are enrolled in the North Florida /South Georgia VHA (NFSG/VHA).

There are 21 Veteran’s Integrated Service Networks (VISN) located across the United States. Within each VISN are local areas that are headed by a VHA major medical center. The North Florida/South Georgia VHA, also known as area 573 is part of VISN 8 and covers areas depicted in figure 3.1.

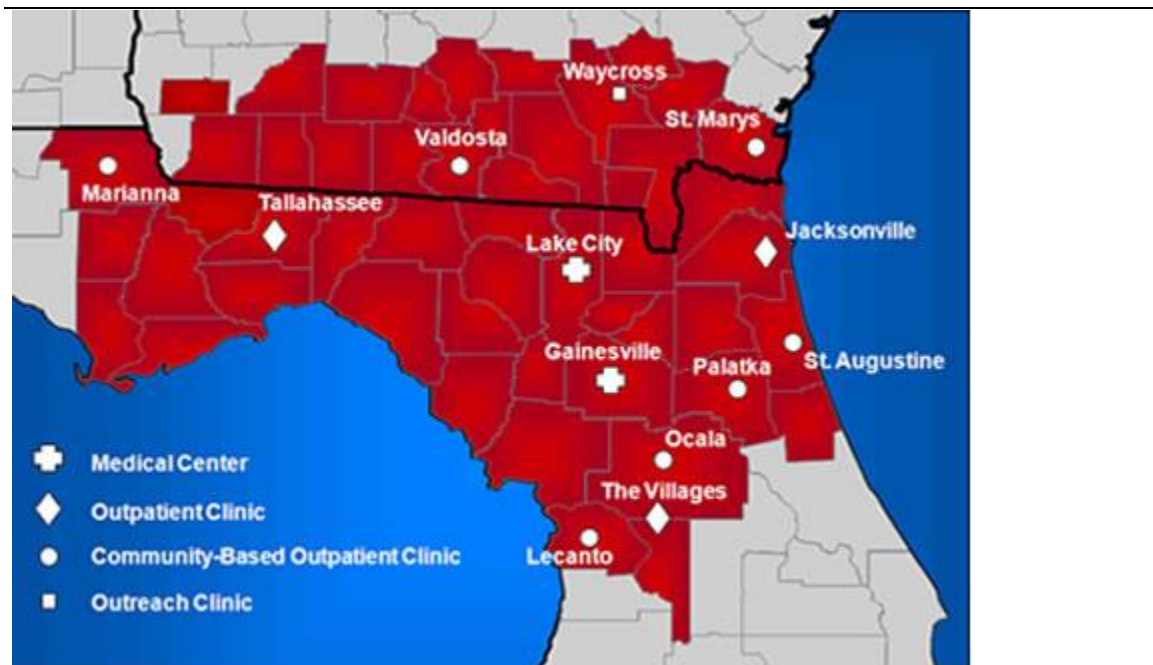


Figure 3.1 VISN 8, area 573 represents the geographic area from which the studies sample was selected (Retrieved from: <http://www.northflorida.va.gov/locations/directions.asp>).

All of the veterans are seen at one of the locations listed in the map, whether it is the outpatient clinics, community based outpatient clinic, or medical centers. At the time of the study, there were 180 caregivers and veterans enrolled in CSP in this VHA. All of the veterans were medically discharged or retired post 9/11 and had service connected injuries/disabilities.

In order to be approved for the CSP, the caregivers must meet the seven primary requirements (see Appendix A) and the veterans’ medical and mental health providers’

(treatment team) evaluation demonstrated a need in the areas of activities of daily living (ADL) assistance and supervision and protection needs. Once the veteran's treatment team determines that a caregiver is essential in the care of the veteran, the caregiver is required to attend a caregiver training offered through Easter Seals. The training is offered in person, online, or via workbook. The curriculum covers five core modules that focus on: Caregiver Self Care, Home Safety, Caregiver Skills, veteran Personal Care, Managing Challenging Behavior, and a resources chapter USDVA (2010). Once the training is completed, a final phase in the application process is a home visit by VHA staff. At this point the caregiver can be approved for the program or denied. If approved, a stipend amount is determined based on clinical assessments by the veteran's treatment team and demographic factors. There are three stipend amounts described as Tier I, Tier II, and Tier III, with Tier III being the highest, demonstrating the most need. The non-taxable stipend once approved, goes directly to the caregiver. The caregiver and the veteran can work while enrolled in this program. The family receives quarterly monitoring when staffing allows with program nursing staff and mental health staff that aims to assist the caregiver and the veteran in addition to telephone support from the team staff.

Sampling

The study used a non-probability purposive sample as the researcher included participants who were already enrolled in the CSP. This sampling method is appropriate because the study explores commonly shared caregiving experiences of caregivers for post 9/11 seriously injured veterans. Purposive sampling is typically chosen when there is a defined area of interest around which sample selection is formed. The goal of the

sampling may not be generalizability, but an exploration of a particular phenomenon (Alston & Bowles, 2003).

Quantitative study

Inclusion criteria for the quantitative portion of the study included enrollment into the CSP program and completion of the Zarit caregiver burden screening tool (Bachner & O'Rourke, 2007). Participants included all types of caregivers including, spouses, partners, parents, and friends. There were a total of 172 caregivers that were enrolled in the program and were used for the quantitative portion of the study. Caregivers who had missing Zarit burden scores (Bachner & O'Rourke, 2007) or other missing data, or who were not enrolled in the CSP were excluded from the study. This researcher is currently the coordinator of the Caregiver Support Program and sought permission from the VHA to complete this study (See Appendix D). Access to this population for study purposes was approved with an expedited IRB review by two IRB's {University of Florida (UF) and VHA}. University of South Florida deferred IRB approval to UF and the North Florida/South Georgia VHA research service (See Appendix D).

Qualitative study

A total of 16 participants were recruited for the qualitative portion of the study. Two letters were sent, four weeks apart, by the researcher to invite caregivers who met inclusion criteria to participate in this study. All of those who responded (n = 16) were invited and agreed to participate in the study. Participants voluntarily participated in the study; honorarium was not provided. Inclusion criteria included participants who were enrolled in the program. The recruitment goal was to include six spousal caregivers with children in the home, six spousal caregivers without children, and four parental

caregivers to maximize the variation in caregiving experiences. In-depth face to face interviews were completed in the caregiver's home or at a location convenient for the caregiver. The researcher met with each participant one time; no additional interviews were needed.

Informed Consent and Confidentiality

Since the quantitative portion of the study was a retroactive file review and used existing program data, a waiver of informed consent was granted by the VHA and UF IRB (See Appendix D). Informed written consent to complete the study and for the session to be audio-recorded was obtained from participants in the qualitative portion of the study with full disclosure about the study purpose (See Appendix D). Participants were advised of the study's risks, benefits, and the right to stop the research, and how their information would be protected and remain confidential. Participants were informed of the researcher's duty to warn of any threats to self and others and also to report any issues concerning abuse and neglect of a vulnerable adult or child. Consents were obtained and all the interviews were digitally recorded and transcribed verbatim. Confidentiality was maintained by assigning each participant a numerical identifier. All VHA data was maintained on site at the VHA and was secured in locked cabinets or saved to the VHA network drives which are password protected and secured behind the VHA firewall. The participants were provided with their local Caregiver Support Coordinators' information in the event they required counseling or support as interviews could have triggered distress. They were also made aware that they could request resources for counseling and the North Florida /South Georgia Caregiver newsletter which listed all the local support groups and programs offered to these caregivers if

requested. None of the participants requested this information during or after completion of the interviews.

Instruments and Measures

Independent variables

Age: Caregiver age was chronological age. Caregivers had to be 18 years of age or older to participate in the Caregiver Support Program.

Race: Caregiver race was categorically coded. There were four groups including White, Black, Hispanic, and other caregivers in the sample, and this grouping was used for analyses (1 = White, 2 = Black, 3 = Hispanics, and 4 = other).

Caregiver type: Caregiver type was categorically coded into four groups including parent, spouse, significant other, and other (1= parental caregiver; 2 = spousal caregiver, 3 = significant other, and 4 = other).

Children in the home: Caregivers with children (ages 17 and younger) in the home were coded as 1 and those without children in the home were coded as 0.

Stipend level: The caregiver's stipend level had three categories (1= Tier I, 2 = Tier 2, and 3 = Tier 3).

Veteran Diagnoses: Diagnoses were coded into three categories (0 = PTSD 1 = TBI, 2 = both diagnoses).

Diagnoses vary based on the provider's evaluations. For the purposes of this study, PTSD was defined as a veteran being diagnosed with any of the following: PTSD, anxiety disorder, chronic adjustment disorder, mood regulation disorder, and depression as most of these are symptoms of PTSD. TBI includes all of the following diagnoses:

TBI, sleep apnea, migraines, headaches, memory loss, and dizziness/vertigo (DOD, 2013).

Dependent variable

In order to measure caregiver burden, the VHA uses the screening version of the Zarit Caregiver burden interview prior to admission of the caregiver into the Caregiver Support Program and annually thereafter (Bachner & O'Rourke, 2007). The scale asks the following questions: Do you feel that because of the time you spend with your relative(s) that you don't have time for yourself? Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)? Do you feel strained when you are around your relative? Do you feel uncertain about what to do concerning your relative? These questions are answered using a five point Likert scale (0 = *Never*, 1 = *Rarely*, 2 = *Sometimes*, 3 = *Quite Frequently*, 4 = *Nearly Always*). These questions have been retained from the original Zarit Burden Scale and measure the domains of personal strain and role strain. A summative score of the four questions ranges from 0 to 16. Any scores of eight and above are considered indicative of caregiver burden.

The Zarit Burden Interview (ZBI) has been used with many different populations and translated into other languages, but primarily focuses on caregivers living in the community and measures caregiver's perceived strain. It is one of the most frequently utilized scales when assessing caregiver burden and has evolved over the years (Bachner & O'Rourke, 2007). The original scale has been adapted several times; the scale is now 22 items with a 5 point Likert scale that measures the following domains of caregiver burden: personal strain and role strain (Bachner & O'Rourke, 2007; Zarit, Reever, &

Bach-Peterson, 1980). It has been validated with a meta-analysis across all populations of caregivers and care recipients in the community and other settings with a higher reliability with those caregivers living with their care recipients in the community. Reported internal consistency for the scale is .86 (Bachner & O'Rourke, 2007).

A short version and a screening version were developed and tested with caregivers in cross sectional, longitudinal, and intervention studies and the psychometric properties demonstrate the reliability and validity of the tools (Bedard et al. 2001). The short version was created using the highest loading factors on the original scale and from that a screening version was developed which took the highest loading variables from all the domains on the 12 item short version scale. The screening tool demonstrated good internal consistency with a Cronbach's alpha $\alpha = .78$. The screening tool was also correlated in this study with the original ZBI in a longitudinal analysis with measurements taken 6 months apart. The two scales correlated at time one and time two with a score of $r = .92$ at both times. The screening tool also correlated well with predicting caregiver burden when compared with the full version of the ZBI in a longitudinal study and the IADL and ADL problem scales which are commonly used with caregivers to assess burden. Overall correlations between the screening version and the ZBI ranged from 0.83 to 0.93 (Bedard et al., 2001).

Qualitative Interview Guide: North Florida/South Georgia Caregiver Survey (NF/SG CG)

The qualitative interview guide was adapted from the FACES qualitative interview guide which was approved at the Minnesota VHA to use in research with caregivers for veterans with polytrauma. Permission was received via email in January,

24th 2013, from Dr. Joan Griffin at the Minnesota VHA to utilize and adapt the interview guide to use in this researcher's dissertation study. The FACES interview guide was developed based on stress and coping theory to adapt the constructs in the guide; these constructs have been retained in the NFSG CG interview guide. The constructs in the guide include: veteran characteristics and well-being, family characteristics, caregiving experiences and well-being, individual resources, objective demands, financial resources, burden, other life demands, social resources (including social media's role), and family well-being. Within the family wellbeing construct, the interview guide for this study adds specific probing about how the children in the home adapted to the veterans absence, return, and how children impact caregiving if the veteran is in a caregiver role. Within the social resources construct, questions were asked about if and how social media, blogging and the internet has played a role in caregiver support. Within the objective demands and financial resources and burden construct, questions about the Caregiver Support Program were added to assess the impact of the program on caregivers and their reported caregiver stress/burden (See Appendix C).

Data Collection and Sources

For the quantitative portion of this study, two chart systems were reviewed to get the information on caregivers and care recipients. This included the VHA Computer Patient Record System (CPRS) and the Caregiver Application Tracker (CAT). CPRS maintains all the veteran's and caregiver's medical records including diagnoses, service connection, certain demographics, and caregiver burden scores. The CAT contains administrative information such as stipend tier levels, amount of time in program, and information privy to program staff such as updates on when home visits are due and

information pertinent for stipend calculations. The participant's records (CPRS & CAT) were reviewed in order to determine the tier level they are receiving, as well as basic demographic information limited to race, gender, age of caregiver, caregiver role (i.e. parent, spouse), veteran diagnosis, children in the home, and caregiver burden score results at the onset of the program. The quantitative data was entered and analyzed in IBM SPSS version 21.

For the qualitative portion of this study, all the caregivers that met inclusion criteria in the program were mailed information about the study by the researcher and they were instructed to contact the researcher if they were interested in participating. Of those who expressed interest in completing the interviews, a phone screening was completed to provide the caregiver with detailed information about the study, the time required for the interview, and their ability to meet with the researcher. For this portion of the study, 16 participants were interviewed, including six caregivers with children, six spousal caregivers without children, and four parental caregivers. The interview was administered to those who met the criteria and consented to participate in the study. All interviews were digitally recorded and transcribed by the researcher. During the interview process, the researcher recorded field notes of observations during the interview and bracketed any feelings the researcher experienced. Bracketing allows for the researcher's own feelings, thoughts, and experiences to be separated from the participant's interpretation of the lived experience thereby reducing any researcher bias (Creswell, 2007; Padgett, 1998). No identifying information was used in order to maintain participant confidentiality and a numeric identifier was assigned to each interview.

Data Analysis Plan

Using descriptive statistics, demographic characteristics were examined. Frequencies were examined for categorical variables. Means, standard deviations, and ranges were examined for continuous variables.

For the quantitative portion of the study, a series of bivariate correlations and means tests were conducted. A Pearson's Product-Moment correlation was calculated to see whether there was a relationship between demographic variables such as age and caregiver burden scores. Two independent samples t-tests were completed to see if there was a difference between mean caregiver burden scores across caregiver gender and caregivers with and without children. An analysis of variance (ANOVA) was used to determine if there are differences in caregiver burden by groups such as diagnoses, race/ethnicity, caregiver type, and tier levels. Correlations provided information such as the strength and the direction of the relationship between variables and t-tests and ANOVA's provided information about difference between independent groups and their mean caregiver burden scores (Mertler & Vannata, 2010). Statistical assumptions for correlation, t-test, and ANOVA were met before the test was administered.

The goal of phenomenological research analysis was to extrapolate the essence of the phenomenon being studied (Hycner, 1985; Lavery, 2003; Moustakas 1984; Willig, 2008), which in this study was the caregiving experience of Iraq and Afghanistan veteran caregivers under three different contextual perspectives. The three different contextual perspectives that were examined in the qualitative study are caregiving as a spouse, caregiving as a parent, and caregiving with children in the home. Phenomenology tries to explore meanings individuals give to a shared experience which may not be externally

viewed from observers (Laverty, 2003). Phenomenological research analysis calls upon the researcher to epoche (bracket) their own assumptions, thoughts and feelings; phenomenologically reduce the data presented; utilize horizontization of all the units of the data; and engage in imaginative variation which will result in textural and structural descriptions that merry to create the essence of this commonly shared experience (Laverty, 2003; Merriam, 2009; Willig, 2008; Moustakas, 1984).

Bracketing or epoché can be achieved by the researcher self-reflecting on their own thoughts about the topic at hand (Laverty, 2003; Moustakas, 1984). This was particularly important because the researcher listened and responded to the challenges and joys of caring for their loved one in her professional role that caregivers shared with the researcher. Bracketing prevents contamination of the data by the researcher's own thoughts and views.

During the interview process, the researcher made notations of emotional responses, and nonverbal cues in order to capture the emotions and intonations of the interviewee in addition to digitally recording the interview. The interviews were then transcribed verbatim. During the transcription process, the researcher notated emotions and nonverbal cues that were present during the time of the interview in the margin of transcription. The transcripts were listened to as a whole from a naïve stance and read multiple times as a whole while the researcher *bracketed* (Laverty, 2003; Moustakas, 1984) their own views and opinions of the topic at hand. This allowed the researcher to have an understanding of the phenomenon being studied and the interview as whole before compartmentalizing the interview. The researcher examined the data free of any assumptions and began the analysis process through open coding. Transcripts were

uploaded into OSR's International NVivo version 8 for the ease of coding (Bolas, Wersch & Flynn, 2007; Hycner, 1985; Willig, 2008).

After reading and being immersed in the transcriptions, the researcher created codes based on the NFSG CG interview guide with guidance from the researcher's dissertation committee co-chair and expert in qualitative research. Before coding all of the interviews, one interview was co-coded with the researcher's committee co-chair to warrant accuracy of the process, and to define the codes and add codes that were not initially created. Then began the process of finding *general units of meaning* by completing line by line coding with the rest of the interviews. These meaningful units were identified throughout the transcripts. Each word, phrase, and sentence individually were examined for meaning. Horizontilization is key to this process where every unit of information is valued no less than the next or previous unit. The researcher still takes an open stance towards the data without taking into account the research questions, theoretical assumptions, or previous knowledge, bracketing their own views (Hycner, 1985; Merriam, 2009; Moustakas, 1984; Willig, 2008).

Next the researcher applied the research questions to the transcribed and coded data, known as *delineating units of relevant meaning*. This begins the process of reduction. Those statements which applied to the research questions were retained, while others were removed. Following this process, the units of meaning were reviewed to narrow down those which are similar and eliminate those which are not relevant to the research questions (Hycner, 1985; Willig, 2008). Negative case analysis was also used where the researcher re-read transcripts to find information that contradicts or opposes the themes and codes already created (Padgett, 1998).

Next the researcher *clustered units of relevant meaning* based on the research questions and theories being used. The context was very important when clustering these units. Contextual themes were then created from the clusters which are the essence of the experiences in the caregivers' own words (Bolas et al., 2007; Hycner, 1985; Willig, 2008). Lastly, the researcher synthesized the patterns in the shared lived experiences of Iraq and Afghanistan caregiving as a spouse, caregiving with children in the home, and caregiving as a parent.

Validation of Qualitative Research

Validation is essential for all qualitative research. As a researcher, one should examine if the information presented in the study is accurate and trustworthy (Milinki, 1999). Prolonged engagement is a method that is used in order to build trust and rapport with the research participants and to reduce any responder bias or reactive responses (Padgett, 1998). In this study, the researcher and the research participants were already aware of one another from interactions via telephone during the course of the researcher's regular job duties at the VHA. To further the sense of trust and security, the researcher had longer interviews with the participants. In addition, peer review/peer mentoring was used throughout the research process to ensure correct methods are being used (Padgett, 1998). Peer review was sought from fellow researchers and the researcher's doctoral dissertation committee. One interview was co-coded with the researcher's committee co-chair and the researcher to define codes and add codes based on each individual's analysis of comparing the two coded transcriptions. This served two purposes; it clarified definitions of each of the codes gathered, but also provided mentoring to the researcher to ensure correct methods were used. Lastly since this is a mixed methods study, methods

triangulation was used. Both qualitative and quantitative research methods were used to try and understand the phenomenon of caregiver burden with this specific population (Milinki, 1999). The researcher compared major findings from the quantitative results and qualitative themes that emerged and found that findings in the quantitative results were supported in the qualitative results and vice versa.

Ethical Considerations

Caregivers are a vulnerable population. They need to cope with major life changes and role changes. Interviews related to this topic may trigger emotions such as sadness or grief, but support services and information were available to these caregivers upon request. A pre-visit phone screening was conducted to confirm the appointment with the caregiver and to verify whether they were still willing to participate in the study. Once the interview started, the caregiver was reminded of the option of stopping the interview if they felt overwhelmed or were unable to go on further. Resources and referrals would have been provided in this event to assist the caregiver.

Another ethical consideration is entering the home of a seriously injured veteran suffering from PTSD. They tend to already have elements of paranoia and like to isolate themselves, so the researcher made every effort to discuss with the caregiver how a researcher might impact the veteran and should this upset the homeostasis of the home environment, the interview could be stopped, moved to a different location, or would not be conducted.

Lastly, privacy had to be considered and protected. These caregivers shared personal information and every effort was made by the researcher to ensure their confidentiality and the veteran's confidentiality. Numeric identifiers were assigned to

each caregiver transcript, digital recording, and the consent form was only accessible by the researcher and the VHA research regulation team.

CHAPTER 4: RESULTS

Chapter 4 provides results from the quantitative and quantitative analysis completed with this study. It begins with demographics and frequencies of the quantitative sample and then provides findings related to various variables (age, gender, race, diagnosis, tier level, and presence of children in the home) and their relationship to Zarit caregiver burden scores. The chapter then shifts to provide demographic variables of the study's qualitative sample followed by a summary of the major themes supported by quotations from the participants.

Demographics of Quantitative Sample

Tables 4.1 and 4.2 present descriptive statistics of the sample for quantitative analysis of the study. There were a total of 172 participants ranging in age from 22 to 69 years old, with a mean age of 39.78 ($SD = 10.29$). The majority of the caregivers were in the age range of 30-40 years old ($n = 65$), followed by 40-50 ($n = 56$), then 20-30 ($n = 29$), and 60 and over ($n = 7$). There were 162 females in the sample (94%), only 10 (6%) were male caregivers. All cared for a veteran with a mental health diagnosis of PTSD and/or TBI, with over 84% being spouses and 9% a parent of the injured veteran. The remaining 7% were a combination of other family members, friends, significant others, or other category. There were 69% ($n=116$) individuals who also cared for a child/(ren) in addition to the veteran in the home. More than half of the sample (59%) were white, 16% were Black, and 12% were Hispanic. A small segment of individuals ($n = 6$) were Asian, Native American, or of mixed and other race. With respect to caregiver burden, as

measured by the Zarit Burden Inventory (ZBI), 32% of the participants screened positive for caregiver stress with a score that was 8 or over ($M = 6.49$, $SD = 3.10$). In terms of tier/stipend levels, 16% received a tier 1 stipend amount (low needs), 41% a tier level 2 (moderate care needs) stipend, and 37% a tier 3 (high care needs).

Table 4.1 Quantitative Sample Characteristics: Mean, Standard Deviation, Skewness

Variables	<i>M</i>	<i>SD</i>	<i>N</i>	Skewness
Zarit (ZBI)	6.49	3.10	167	0.35
Caregiver Age	39.78	10.29	172	0.63

Table 4.2: Quantitative Sample Characteristics: Percentage and Frequency

Variables	Percentage (%)	Frequency	<i>N</i>
Caregiver Sex			172
Male	5.8	10	
Female	94.2	162	
Caregiver Type			172
Friend	0.6	1	
Other	1.7	3	
Parent	8.7	15	
Relative	1.7	3	
Spouse	83.7	144	
Sig Other	3.5	6	
Caregiver with Child/(ren)	69.2	116	167
Veteran Diagnosis			172
PTSD	80.8	139	
TBI	42.4	73	
Other MH Disorder	19.8	34	
PTSD/TBI	33.1	57	
Tier Level			172
Tier 1	16.3	28	
Tier 2	41.1	81	
Tier 3	36.6	63	

Table 4.2 (Continued)

Variables	Percentage (%)	Frequency	<i>N</i>
Caregiver Race			162
Asian	1.2	2	
Black	15.7	27	
Hispanic	11.6	20	
Mixed	0.6	1	
Native American	0.6	1	
Other	1.2	2	
White	57.6	99	

Quantitative Results

Quantitative research questions 1 a & c

What are the predictors of caregiver strain? What are the relationships of demographic characteristics (e.g., age, gender) to caregiver strain? Are there differences in the predictors of caregiver strain between caregivers with children and those without children? Table 4.3 represents the t-tests that were conducted to determine if there was a significant difference in ZBI means between male and female caregivers, and caregivers who had children versus those without children in the home. There was no statistically significant difference between male ($M = 4.89$; $SD = 4.51$) and female ($M = 6.58$; $SD = 6.58$), $t(165) = 1.60$, $p = .11$ caregivers' ZBI scores. However, there was a statistically significant difference between caregivers who had children ($M = 6.84$; $SD = 3.21$) versus caregivers who did not have children in the home ($M = 5.57$; $SD = 2.75$), $t(160) = -2.36$, $p = .02$. Those caregivers who had children in the home had a significantly higher caregiver burden score compared to caregivers that did not. A Pearson's correlation analysis was completed to determine if there was a correlation between caregivers' age and their ZBI score. There was no relationship between the two variables

($r = -.14$). Age did not result in any trends with relation to the caregiver burden stress in this sample (see Table 4.3).

Table 4.3: Correlations and T-Test Analysis

Independent Variable	Dependent Variable	
Age	Zarit Burden Scale	$r (167) = -.14, p = .07$
Gender	Zarit Burden Scale	$t (165) = 1.59, p = .11$
Children*	Zarit Burden Scale	$t (160) = -2.36, p = .02^*$

Quantitative research questions 1 a, b, d & e

What are the predictors of caregiver strain? What are the relationships of demographic characteristics (e.g., race) to caregiver strain? How do parent caregivers differ from spousal caregivers when comparing caregiver strain? How does diagnosis (TBI, PTSD, or both) affect caregivers' levels of strain? What is the relationship between tier levels (higher level equals higher level of care) and caregiver strain?

Table 4.4 represents the univariate analysis of variance tests that were completed to determine if there was a difference across groups such as race, caregiver role, tier levels, and veteran diagnosis to caregiver burden scores. Results indicated that there was not a significant difference across race, tier levels, and veteran diagnosis to caregiver burden scores. Therefore, in this sample, the caregiver's race, the amount of their tier level, and the veteran's diagnosis did not have an association with ZBI scores. When a univariate analysis of variance was conducted across caregiver role (parent, spouse, significant other, and other) there was a significant difference noted across caregiver role and ZBI ($F [3, 159] = 1.59, p < .01$). Tukey's HSD post hoc testing resulted in a difference between parental caregivers ($M = 4.46; SD = 2.70$) and spousal caregivers ($M = 6.83; SD = 3.10$) with spousal caregivers having a significantly higher ZBI score. This

result demonstrates that spouses tend to manifest higher stress with caregiving than parents do (see table 4.4).

Table 4.4: Univariate analysis of Zarit Burden Inventory

	Source	SS	Df	MS	F
Tier Level	Between Groups	30.32	2	15.16	1.59
	Within Groups	1563.39	164	9.53	
	Total	1593.71	166		
Race	Between Groups	42.70	3	14.23	1.54
	Within Groups	1424.97	155	9.19	
	Total	1467.67	158		
Role	Between Groups	107.42	3	35.81	3.89*
	Within Groups	1463.31	159	9.20	
	Total	1570.74	162		
Diagnosis	Between Groups	42.70	3	14.23	1.55
	Within Groups	1424.97	155	9.19	
	Total	1467.67	158		

Note. * $p < .01$

Qualitative Descriptives

The sample for the qualitative study included 16 participants. Table 4.5 presents the characteristics of the sample. The sample was divided into three sub groups: parental caregivers ($n = 4$), spousal caregivers ($n = 6$), and spousal caregivers who have children in the home ($n = 6$). The mean age of the sample was 49.25 years old ($SD = 11.79$).

There were a total of three male caregivers and 13 female caregivers who were interviewed. The majority of the sample were Caucasian ($n=10$), four Blacks, and two Hispanic caregivers. Among the parental caregiver (PG) group, the mean age was 64.5 ($SD = 7.04$) and the group was equally representative of males and females with three

Caucasian caregivers and one Hispanic caregiver. Within the spousal caregiver (SG) group, the mean age was 49.33 ($SD = 4.08$) with all participants being female. There were three Black, two Caucasians, and one Hispanic participant in the spousal sample. Five of the spousal caregivers did have adult children that were no longer residing with them and one participant chose not to have any children. The last group was the six spousal caregivers with children in the home (CG). The mean age of the caregivers was 39 ($SD = 7.67$); there were five females and one male caregiver in the group. Five individuals were Caucasian and one was Black. All had at least one minor child in the home that they were caring for full time.

In total, there were 13 females and 3 males, 10 Caucasians, four Black, and two Hispanic caregivers interviewed. All of the caregivers lived with the injured veteran. All of the veterans were diagnosed with PTSD and/or TBI. Two of the spousal caregivers interviewed were veterans themselves, and one other spousal caregiver grew up in a military household.

Table 4.5: Qualitative Sample Characteristics

Group	Race	Age	<i>M</i> Age	Sex
Parental Caregivers (PG):	3 Caucasian	68, 69, 67	64.5	2 M/1F
	1 Hispanic	54		1F
Spousal Caregivers (SG):	3 Black	54,49,45	49.3	6 F
	1 Hispanic	52		
	2 Caucasian	44,52		
Spousal Caregivers with Children (CG)	1 Black	49	39	
	5 Caucasian	34, 29, 37, 38, 47		
Totals: $n = 16$	10 C, 4 B, 2 H		$M = 47$	3 M; 13 F

Qualitative Results

Qualitative research question 1

What are the lived experiences of spousal and parental caregivers of veterans returning from Iraq and Afghanistan? Are there differences between the lived experiences of spouses and parents? Twenty-two major themes emerged from the qualitative interviews with positive and negative subthemes for most which created the shared lived experiences of these caregivers. Table 4.6 represents the most prevalent of the 22 major themes along with subthemes, in descending order.

Table 4.6: Research Question 1: Major Themes and Subthemes

Themes	Subthemes	References
Family Adjustment		
<i>Positive Subthemes:</i>	New Normal, Expertise In caregiving, Family Characteristics, Vacationing, Traditions, Shared decision making, humor, planning ahead	216
<i>Negative Subthemes:</i>	Jealousy, Maladaptive family characteristics, lack of trust, veteran isolative, readjustment difficulties, veteran in child role, lack of cooperation, communication, loss of self-veteran, lifetime commitment	111
Subjective Demands:	Emotional and cognitive demands, emotional labor, emotional façade, veteran's behavior challenging, psychological demands	184
Coping Techniques:		
<i>Positive coping:</i>	Empowering, resilience, walking away, creativity, empathy, intuition, refocusing, patience, understanding, advocating, balancing independence of vet	127
<i>Maladaptive coping:</i>	enabling, avoiding Vet, avoiding emotions, caregiver feeling like vet won't survive without her/him	45

Table 4.6 (Continued)

Themes	Subthemes	References
Social Support:		
<i>Positive Codes:</i>	Utilizing social support, using social support to direct veteran, adult child as a caregiver	56
<i>Negative Codes:</i>	Not sharing resources, friends/family enabling, undermining, not using support, using only in emergencies, lack of support, loss of support, anger at support for taking advantage	64
VA/DOD:	Services as helpful/barrier to caregiving	31/87
Self-Care:	Practicing self-care/Lack of self-care	56/14
Intimacy:	Positive intimacy/Negative intimacy	20/50
Role Strain:	Balancing roles/Stress with roles	57
Financial Resources:	Positive impact/Negative impact	24/14
Life Course:	Life course changed/ Life course unchanged	52/4

Note. Table 4.6 represents the 10 most referenced themes of a total to 22 that describe the shared experiences of the qualitative sample. Additional 12 themes in order of prevalence include: Obligation; Rewards; Isolation/Loss of Self; Reciprocity; Stigma; Community Resources; Spiritual Support; Tools; Hope; Uncertainty; Guilt; Leash Syndrome

There were additional 11 themes that were created, but they did not capture a shared experience, rather highlighted some themes that less than half the participants identified. These themes included feeling resentful or other's feeling entitled; military caregivers (caregivers who had "boots on the ground," i.e., a veteran themselves); objective demands-such as physical disabilities and equipment used to assist with those; previous caregiving experiences (caregivers that had been a caregiver in the past and how

that assisted or compared to current experiences); monotony (the feelings of having the same routine/schedule and how that makes caregiving easier or harder); service animals and pets (how they assisted caregivers/veterans); grief-the feeling of loss associated with caregiving); fear, specifically being fearful of the veteran; whether caregiving was an expected or unexpected role; and lastly employment as a protective factor against caregiving stress.

Family adjustment

Family adjustment was the most prevalent theme in the interviews. All 16 participants shared experiences that were both positive and negative in reference to how their family adapted post injury. Positive and negative subthemes are described in Table 4.6. Some caregivers described how the family adjusted in a positive sense:

CG: We're young and flexible, malleable we can bend if we need to...

CG: ...for July 4th ... we went to parking lot by babies r us...my dad kinda of helped out in trying to find a place where the kids could see fireworks for the first time and get the enjoyment of it, but not have it effect my husband...we were far away from them, he also wore his noise cancelling head phones...the kids got to see fireworks for the first time last year and their 8 and 6, so it's been a while, but were trying to get him to step out of his comfort zone and he did. It was baby steps, but hell, I'll take baby steps.

CG: And we've learned to adapt and I don't wanna say overcome, but, we've learned how to live with it to the point that things can be comfortable for us. They may not seem normal for other people, but it's comfortable for what we can endure. Um, we're isolated...but, that's by my choice in terms of making sure he's comfortable, not putting myself out there...it's catch 22, you want to be able to have a social interaction, but at the same time, you don't...We take it day by day because we can't take it any other way.

All 16 participants also reported some negative adjustments to the injury:

SG: One of things that I thought that we would do in retirement also is spend a lot of time with the grandkids and we do, but not as much as we had anticipated because he can't always tolerate them if that makes sense.

CG: Her insecurities and me being at work was definitely a mood changer for her. You know that it would set her off in ways, it would make her jealous, it would make her insecure.

PG: Reclusive, extremely reclusive, uh, has crowd issues, sometimes, you can get him out of the house.

Overall, there were more references to positive adjustment than negative adjustment with spouses with children referencing the highest percentage of positive adjustment. In terms of spousal and parental caregiver differences, spouses referenced more instances of positive adjustment than parental caregivers, but they also reported more negative instances of adjustment than parents as well. So while spouses were able to identify positive aspects of their families' adjustment to their new role and circumstances, it was not without many instances of family disruption.

Subjective demands

Subjective demands, the second most prevalent theme, centered on emotional and cognitive demands, particularly challenging behaviors that resulted in stress in caregiving. Interestingly enough, there were no positive references in the interviews with regard to this theme. All subjective demands resulted in negative subthemes and responses from the caregivers interviewed. Spouses referenced more issues with emotional and cognitive demands than parents, however of note, the spousal caregivers with children (CG) dealt better with the emotional and cognitive demands than both spousal caregivers (SG) and parental caregivers (PG).

SG: But I have been called quite a few things. He had never before the deployment, he had never called me an "FB" and I got called one of those and several times you know, a few other things. I was just devastated. And then once he was upset and umm, he he said that if I did not move he was going to beat the s-h-i-t out of me and he would have never done that before.

CG: He has a lot of anger issues and um some days it's like walking on egg shells you know and in his own mind he feels like he's a burden, he's made

comments to me like that before like you know you would be so much happier if you weren't in this situation and this and that so, um, think by now you know that's the struggle for us now, the day to day pieces. He says things like man it was so much easier in Afghanistan and I'm like well what, what?!?!

PG: Emotionally, I'm exhausted. I just cannot deal with all this drama. You know and I don't feel like I have an outlet. You know I'm just, keep internalizing everything. And then when I can't take anymore, I scream at him a little bit and then I feel a little bit better for a little while and then more drama hits.

Coping techniques

Coping techniques were used by all 16 participants. Subthemes in this category centered on positive coping techniques such as empowerment and resilience, and maladaptive coping techniques including enabling and avoiding emotions. Overall, there were more positive coping techniques used than maladaptive with spouses using more positive coping techniques than parents. Spouses tended to use more empowerment and focused more on trying to ensure that the veteran maintained some sense of independence rather than dictating to the veteran:

SG: ...remember I told you he likes the washing machine. I just have to have certain detergents in order for you to do it. I even work around that, cause I know you're gonna put more than that one scoop, so I work with you to at least make you think that things are going your way.

CG: Yeah, I've come up with a lot of strategies to get him to do things without having to make him feel bad about him and that sort of stuff so.

All parents interviewed utilized maladaptive coping skills that inadvertently resulted in enabling the veteran.

PG: And I wash his clothes and I wash his sheets and that kind of stuff but it's not no, I probably should be making him do that, but it's just easier to do it then it is to let him pile it up in the bedroom. But no I still have my time. Nothing's changed. He doesn't eat breakfast, he doesn't eat lunch, he does eat supper with us, but that, basically it.

Most of the spousal caregivers (SG) and parental caregivers (PG) felt that the veteran

would not be able to survive without them, with only two of the spousal caregivers with children (CG) reporting the same:

PG: It's harder for me because I'm his mom, but I don't trust him with anybody else, because I think I do it best because I am his mom and even if I was taking care of someone that wasn't my mom, I would think that whoever they had before or anybody they have after me, will not be as good as me.

SG: I can't think of anyone else I'd rather, that I would trust to do this for my husband more than me.

Social support

Social support was a shared theme that all 16 participants discussed. Negative and positive aspects of social support (peer, family, and friends) were discussed. Negative attributes of support systems included social undermining, lack of social support, and not using social support. Positive aspects referred to the ability to utilize a support system for assistance for emotional support, respite, and using social support to provide direction for the veteran. Participants had more negative experiences with social support than positive. Parents used social support less than spouses and this resulted in less negative experiences for parents with social support. Spouses and parents both discussed some of the problems associated with or reaching out to social support:

SG: His family, they feel as though there's nothing wrong and that it's me that's causing all the problems. Because they can call him and ask him how he's doing and he's like fine, I'm good and you know all this kind of stuff. But then they'll call me and ask me and say well he's having a day or something like that, so um, they just I don't think that they want to understand. I don't think that they want to know.

PG: I don't have friends like I'm a loner. I never used to be that way, but I'm that way because I have to be careful who I bring in my home because majority of the people that I know, they knew my son since he's young so when they come over and they see my son, they'll make comments like what happened to him?

One spouse reflected positively on how social support was used to assist in caregiving:

SG: Not trying to do it myself or not trying to hold everything in, but when things happen, having a support and a network I can actually reach out to and talk to about it and they really understand. That makes it easier. And usually in those times they can even say, oh I've been there before, you know, I remember when my husband was baker acted...I'm like what...you know (laughing). And it makes it easier that way.

VHA and DOD services

All of the participants discussed aspects of the discharge process with the Department of Defense (DOD) and the intake process and continued medical care within the Veterans Health Administration (VHA) and the Veterans Benefits Administration (VBA). All participants described services as being challenging, whereas only 13 participants offered praise for the systems, with spouses being the majority of those. Many of the participants found the VHA and DOD doctors, case managers, and other services to be helpful. In terms of challenges, many participants struggled with navigation of the systems, coordinating services within the VHA with outside services, and turnover to name a few. The most prevalent issue was navigating both the benefits and the health care services that the VHA offered:

SG: Dealing with the VA was very difficult you cannot imagine at first. I cried so many times. The first two or three years, it was horrendous.

CG: But navigating the VA system and getting him back seeing a psychologist, which is like top tier of importance you know, that was really difficult, even still that's why he goes to a psychologist provided throughout Tricare

PG: We were driving him three to five hundred miles a week on our dime, he had no money. We were living off his social security...We were going to food banks for food. I mean we were just desperate and they (VA) wouldn't pay for travel vouchers cause he didn't have a rating...that was when we first started taking out loans just to try and take care of him.

Some of the challenges that were faced involved being discharged from the military with no guidance from DOD and a lack of a navigator on the VHA/VBA side:

CG: Having support, having somebody who's been through it, who can guide you, not really hold your hand but at least give you the direction you may need to know to get the support you need or get the help that you need. Um not having that and having to navigate it on my own, I've learned a lot and I've probably learned a lot more than other people may have or ever will have, or maybe I haven't learned as much as other people, but having somebody to kinda of guide you through the process, when he first got out.

Others found the VHA medical doctors to be barriers for the caregivers:

PG: But the caregivers never asked anything. Nothing, zero! The doctor won't even call back the caregiver. And that's where I think the system needs to change, that I think they too, the doctors, need to start recognizing that the caregivers are like sometimes the life line of these soldiers or these veterans. You know cause we are their life lines.

Despite the negative aspects of transitioning from the military to the VHA, there were many positive aspects mentioned as well:

SG: Well the VA has made caregiving easy for me. They have been receptive and nice and kind and all that. And usually when we go to the VA, it's rare if you get a cranky VA person, usually they'll even tell you directions and things like that and it's usually not a problem...I went to audiology, I told the lady I didn't know how to get new batteries, so she gave me a hand full of batteries and she gave me the form and told me just fill out this form and send it in and they'll send you some batteries and I thought that was nice of her to take time to give me some batteries and take some time to renew your book when you're checking out a book and so forth and so on.

SG: PCP is amazing. He has called our house at 9 o'clock at night to check on him. I'm like, "are you still at work?" He's like "no I'm home," but I'm just making phone calls, following up, finishing paperwork, making calls and he goes, here's my home number if you need to call me, call me after 8 o'clock that's when I get home.

Self-care

Self-care was defined in the study as participating in activities or being aware of the need to take care of one's self emotionally and physically to help manage stress. The majority of the caregivers were aware of self-care and were practicing some form of self-care. Despite being aware, there were some that were unable to practice proper self-care

and for many this resulted in health-related consequences. Those that practiced self-care engaged in activities such as counseling, gardening, reading, music, journaling, sewing and fishing.

SG: Knowing when to stop, I mean there are days that I could go on the whole day. You know what, I've had to schedule time in my calendar to eat and I have to set alarms so that my phone goes off when it's time to eat, because if not, I'll be sitting at the computer or on the phone with doctors and I or in his files working and the whole day'd be gone. So I have to learn how to balance the time and balance the day better so I can take breaks, because caregiving is demanding. Well the caregiving that I have to do for him is demanding.

For those that were not practicing self-care, it had some significant consequences such as being diagnosed with a mental illness or physical illnesses which in some cases resulted in hospitalizations.

PG: So yeah, there's been some depression and I think that was uh part of my problem when I finally found a doctor down here and she run all kinds of tests and we decided yeah you need some of this and you need to do this.

SG: So I was hospitalized a couple of times for um high blood sugar, being diabetic. I had pneumonia, I mean it, I knew I was feeling bad, but I just brushed it off, kept going.

CG: My health has gone down because you take care of them. Like I said my needs and wants are last in line if they're even in line. I take care of him and the kids. Those are the two, the higher for a priority. Um, their needs and wants, my needs and wants are last.

Spouses were less likely to practice self-care compared to parents. There was only one reference from a parent who reported a lack of self-care. Overall, the SG were identified as not practicing self-care compared to CG.

Intimacy

Intimacy was defined as an emotional connection with the veteran, including physical and emotional intimacy, i.e. sex, kissing, touching, hugging, or bonding. Of the 14 participants who spoke of intimacy, 13 described negative consequences, and 8

discussed some positive aspects of intimacy within their relationships with the veteran. All except one of the spouses reported a concern with intimacy. One parent reported concerns, but overall spouses were most impacted.

CG: I look at him and there's sometimes where he just acts so bad and so just like you know he's in my face yelling at me and I'm like but then he expects me to turn around and be intimate with you, I can't just let that go.

PG: ...now he walks in and his eyes are just devoid of any emotions. He has no emotion no feeling,

Despite the concerns with intimacy, some spouses did report positive references with regards to intimacy, with the majority being spouses with children.

SG: Well we always make sure we kiss each other good night, or when one of us leaves we kiss each other good bye. We say I love you a lot. We will hold handouts in public.

CG: But um, for me and him there's a connection and I think that's because we were together before he was hurt. I think it's still there. I think it's less than what it could be, but and I hope, that at some point it might get better, but there's still a little bit of one.

Role strain

Most of the participants ($n=13$) discussed how they felt torn between multiple responsibilities including taking care of children, other family members, struggling between the roles of being a spouse versus being a caregiver, and experiencing challenges with finding time to manage all of their roles. Not surprisingly, the ones that were most affected were the spouses, particularly those with children. In fact, all of the spouses with children reported this as a concern whereas only five spouses without children and three parents reported the same concern.

SG: Um, I had a responsibility of making sure the household is run and kept clean and you know bills are being paid and you know everything. Even though the girls in college, still have to do things for them and um, he makes it difficult when he lashes out.

CG: ...each person may have to understand look, I'm gonna get to you but I'm doing this, sometimes it's a strain also because you know one person may think well you're not giving me attention or you're not listening to what I'm saying you feel like you're being pulled pretty much you know and then it just comes to a point where I mean for me I have to tell myself look, when you get to it, you get to it, cause you're just gonna go nuts...I find myself flustered and panicking...I just need to stop breath and count to three

Parents discussed the challenges of caring for the veteran and the veteran's children:

PG: The most difficult thing...is the amount of pressure placed on mom (veteran's mother) because of his children. Because he is a good father, but if mom is around, he's gonna sit back and let her do all the work.

PG: ...they both (veteran and his spouse) were just out of control, but there was children and that's what I was concerned about the children.

Parents also shared how the veteran's failed relationship(s) was a source of strain they often had to mediate and assist:

PG: ...and he's married but getting a divorce...And she is doing everything she can to cause him increased pain and his position in regard to the divorce is to say that he isn't fit to take care of the children because of PTSD and TBI which his attorney is gonna fight because it simply isn't true

Eight spouses felt that they were taking care of a child with respect to the veteran's behaviors and the need to supervise him/her. None of the parents expressed this as an issue or concern.

CG: You know I get real upset when (veteran's name) thinks I'm treating him like a mother you know because that's not what I'm trying to do and you know I try to explain to him, I know you see this as nagging, but if I'm seeing where you're not taking care of yourself, I have to do what I have to do.

Finances

Financial security was discussed with each of the participants. All of them discussed some aspect of finances in terms of experiencing financial challenges, positives and negatives associated with having control over the finances, and whether they were secure financially. This population is unique in the sense that they are receiving a

financial stipend for caregiving, in addition to the veteran being compensated for his service connected disability. Some veterans were also receiving social security disability. Only two of the 16 caregivers were working, and only one injured veteran was employed. Six participants reported feeling financially secure, with five being spouses and only one being a parent.

CG: Luckily, financially with he and I both being retired military and especially with him getting injured and everything, finances aren't an issue.

Seven spouses and three parents reported financial challenges. One of the parents discussed the struggles they were having as a result of caregiving later in life:

PG: Well when I first became his caregiver, was the financial because he hadn't been diagnosed yet so he was getting nothing and we were having to financially support him...Well he got behind on support (child) before he moved down here with us and then that was a catch up time and I know we tried not to make him feel that it was his fault, but I know he felt that a lot of times that he felt guilty that he had gotten us into a situation like this and I think that was the worst part then. And then when he started getting money that wasn't a whole lot better because he just went nuts like I've got money I can go out and I can do this...he doesn't know how to manage his finances. I pay his bills for him. Or they probably wouldn't get...

In terms of controlling the finances, two spouses and one parent found this to be challenging and a source of stress, whereas nine individuals, with the majority being spouses (8) found that having control over the finances in the household made caregiving much more easier. One spouse discussed how she had to assume this role as the household finances were getting out of control:

SG: I realized is that I needed to do in order for us to survive because he wasn't doing a good job at it (laughing). It was a job that I tried to relinquish, but the money wasn't adding up...so I had to take that job and I had to become assertive and I had to take care of us. I had to take care of us.

Life course

For these participants becoming a caregiver resulted in many changes in the course of life such as changes in their hopes and dreams for the future, career changes, and changes in family planning. Of the 16 participants interviewed, 13 reported some aspects of their life course changing, mostly for the negative. One of the spouses talked about how she wanted children, but decided it would be selfish for her to have them now due to the veteran's injuries "So, um, pre injury, I envisioned my relationship to include children. Um, a family with my husband." One of the parents shared how she avoids thinking about all the things they have given up in order to provide care:

PG: Sucks...I, you know, if I sit and think about it, it just really sucks, otherwise I try not to think about it as far as my emotions. I have depression just like he does. Um you know if I let myself stop and think about you know where he could end up at or how he could end or where we could end up, so emotionally I try not to think about a lot of that stuff. I try to take it one day at a time.

One spouse while calm and humorous throughout the whole interview began crying when asked about her life course changes. The loss of her career and educational goals was one of the most devastating changes in her life as a result of caregiving:

CG: I was going to school cause I was gonna teach (crying) and try to finish my master's degree...I did finish the master's degree, but it's not, it's not one that allows me to teach..., I would have to go through a regular teaching program in order to teach at high school and it's just so much money...The student loans I have are deferred because of our situation...but I can't take out more loans when you're in a deferred situation and it would be impossible I think to manage the amount of time going back to school yet again it would take. So (crying more) I'm sorry.

Obligation

All participants voiced feelings of obligation in caring for their loved one, whether they stated it explicitly or they insinuated it. Some caregivers felt it was not an

obligation, but rather a choice to provide care, however, they also expressed that no one else would be able to provide care and therefore it was a role that they had to assume:

SG: I think it just kind of fell into my lap since I was his wife and at that time our kids were younger so they couldn't do it. He doesn't have a relationship with his family so, I was the one.

PG: You know, so no I don't feel obligated to take care of him, but he is my son and I would never let him fall.

CG: It's love, it's a lot of heart, it's a lot of self-reliance, I've gotta be there for her even when I can't be there for myself, its hard work

Rewards

Rewards were defined in the study as any kind of joy or pleasure the caregiver might experience in the process of caregiving. Everyone, with the exception of one caregiver, reported that they found some rewards in caregiving, albeit it took many participants some time to come up with an answer. "Huh...I don't know (long pause)... Maybe feeling that he has a better life than he had before." The majority found it rewarding to witness the veteran make small steps towards recovery or a glimpse of who the veteran was pre-injury. One of the spouses reported how she envisioned her new role and how rewarding it was:

SG: To me, um, this might sound kind of weird. I know a lot of people probably would not agree with me, but when I look at that emblem, the wounded warrior project has, the soldier carrying the other soldier, I think about that as a caregiver. You know especially being married, cause I know I carry my husband. I carry him, I support him, I help him and so that's what to me the caregiver just gonna be there to support, to carry, to help, you know.

One spouse talked about how she felt when she sees examples of the veteran pre-injury and the hope it gives her:

CG: That he's still around. That he's still alive and sometimes I get a glimpse of him that it's like, ok it's worth it and there may not be a lot of

emotionally connection with him at times, but every once in a while there. So having the emotional connection with him we're like ok, I still love you no matter what what's going on with you, I still love you and I still care for you so. Just every once in a while I get that glimpse.

One spouse, when asked what the rewards of caregiving were, began to laugh and stated

“Nothing, absolutely (laughing), absolutely nothing!”

Loss of self/independence

Most of the spouses reported that they felt as if they had lost their own identity including a loss of hobbies, social lives, and an overall feeling of loneliness.

Interestingly, none of the parents felt this way, only the spouses and with no discernable difference between spouse with children and those without children in the home. One spouse reflected about the profound impact caregiving has had:

SG: My independence and my, I've lost myself in all of this because I'll, the little sleep I get up, I wake up and it's about him, all during the day it's about him and I never have time for me...I can't see past the day that I'm in, I don't. I feel so consumed in taking care of him that I kind of forgot about me.

One caregiver talked about how difficult it was to transition from having a career to being a caregiver:

CG: I've been the guy on the jobs for 20 years that everybody was coming to me to get my paycheck on Friday and I was telling everybody what to do for 8 hours a day and they were listening to me, and I was the man.

One caregiver spoke of how the PTSD has impacted her life:

CG: He's not comfortable around people, so slowly lost the, I guess in person type of friendships. The only friendships I have now are with my friend she lives in TX, so even then, it wouldn't have been in person, but we don't get that contact. We don't go out to dinner, we don't go out with friends. We don't do any of that stuff. Heck we don't even do it with just the two of us. You lose that and so and because of how isolated he and how he's not comfortable around those people you tend to lose your own. You kind

of lose a sense of yourself at the same time and I know that that's a lot. That happens a lot with caregivers, you have to try and work, that something you have to work at to try and keep.

Reciprocity

The majority of the caregivers spoke about reciprocity in the relationship with the veteran. Most felt there was reciprocity in the relationship at times, however, the spouses (SG), especially the spouses without children (CG), felt that there was not equal reciprocity. Parents (PG), on the other hand, did not voice any concerns with unequal reciprocity. Reciprocity was defined as a relationship within which there was give and take between the veteran and the caregiver.

SG: Because I think that if something were to happen to me, he would be there. He would take care of me. I know that it's not his fault...

PG: Yeah, with respect with what's going on with him right now with the divorce, I, he'll ask me advice and I'll give it to him and we'll discuss it, and then the decision is, he's 32 years old, he's an adult, he has to live with what decision he makes, so in that respect its joint decision making process.

Unequal reciprocity was defined as when one person felt they were giving more in the relationship in terms of time, effort, and support than the other person. One spouse spoke about how she is able to let the veteran think he was contributing when in actuality he was not:

SG: ...I feel like it's give and take because sometimes, I'll allow you to think you've made the decision when you haven't and sometimes, when I want apples and your steady going towards oranges.

Stigma

Nine caregivers discussed how they experienced some form of stigma. Stigma was described in several categories including stigma as a result of having invisible injuries, undefined stigma, racial stigma, and stigma in the role of caregiver. Spouses experienced the most stigma, with only one parent experiencing stigma. All the spouses

with children experienced stigma compared to only two spouses without children. One of the spousal caregivers with children (CG) described how even she has to remind herself that her husband is injured because his injuries are not visible... “I still look at my husband every day and forget.” One spouse with children talked about how even during an everyday outing people will look at her family and think none of them are disabled.

CG: I definitely think that there's judgment, you know like um, they'll be times where we'll go to Walmart. You know we have handicap placard, so you know they'll be times like you know, I don't look, I probably judge that if we get out of the car with a young child and the handicap placard, I have no doubt that we're judged.

One parent described how when her son returned from combat, he never reintegrated back into civilian life and how others judged him.

PG: You know now that I understand a little bit more about his injuries even though people look at him and he looks ok, their like inside him invisible and nobody knows. Oh well he seems ok and then when they stay around him a little bit then they go what's wrong with him. Why's he dropping things, why's he forgetting things, why is he sweating why's he nervous you know, you know so he has his whole way of life has changed. He thinks that he can live in society and be ok but there's too many triggers.

Community resources

Resources were used by both spouses and parents (11 total) to assist with financial resources, reintegration, and care for the veteran. Spouses tended to have more negative experiences with resources versus parents. Wounded Warrior Project was one of the most prevalent resources used, particularly for retreats and activities that the caregiver could do with the veteran such as cooking classes, educational resources, and respite for the caregivers. Some community resources presented as challenges to caregivers due to red tape, while others came to rely on them. A parent described how

due to the lack of VHA programs, they had to seek outside agency support in their journey as a caregiver.

PG: I think the VA could have offered more so we didn't have to look at outside resources. Um wounded warrior and independence fund have been life savers. I mean they have helped us through a lot. And I really appreciate all they done.

Police organizations and senior centers have also provided resources to caregivers:

PG: In Jacksonville...we have a task force there for the veterans that as long as you don't call the 911 and as long there are no weapons in the home, they will come out and they will assist you in helping that soldier or that veteran. They will not take them to jail...but they have stepped in... and told him they wasn't there to arrest him or anything and when he said do you want to go in the car or you wanna take a walk or, and they walked with him, talked with him, you know told him the pros and the cons.

SG: Well one place that we received support is from the senior citizens. The senior citizen is not like an adult day care or anything, it's just old people helping old people (laughing).

Negative comments centered on inequalities in accessing resources with multiple agencies such as Wounded Warrior Project and Homes for Heroes:

CG: ...like the homes for heroes, we know people, that personal opinion, they shouldn't have been given a home because they can financially afford it whereas other people that really need them, can't get qualified for it... and then what may start out as a good intention organization becomes so commercial that, they stop looking at the little people that are there to help um.

Two spouses discussed how the Wounded Warrior TRACK program (a program that assists injured veterans with education and career placement) became a challenge as it created more stress and an additional burden as she was trying to help the veteran succeed in the program:

CG: No it's not happening, we will do school on our own and I will help and I will get you involved with the disabilities people at school because, you know, track has gotten him tied in with those, but there is ton of other responsibilities that they place on those people and people with TBI and

PTSD just can't handle those not to mention physical limitations as well. You know, you can't remember your own address, how are on earth are you gonna remember to manage all these classes remember where you gotta go, how are you gonna remember that you know $2x + 4 = 6$, and $x = ?$

Spiritual support

Most of the participants discussed how important spiritual support was throughout their caregiving journey. Spiritual support came in the form of religious beliefs for all the participants. There was no difference between spouses and parents in terms of spiritual support.

SG: I would say the faith does because I like, I have a devotional that I'll read every morning or if I'm having a special time, I have verses that will come to mind and reminded me ok, he gives me the strength to get through the day, don't worry about tomorrow cause it has its own troubles and things like that. Those things really help.

One of the spouses was crying when she described some of the difficult times she experienced while caregiving. She talked about how verbally abusive her spouse was and how her health was impacted as a result of caregiving. This caregiver and two others described how they even came to question their faith:

SG: Yeah (crying), yeah...um, especially with him, I question why him why me why us, you know to go through this. And then as far as my health, um, I question why you know, put me through all of this you know during this time. I was really angry at one point, I was angry at God, uh, I was angry at him (veteran) for a little while, but through it all, I'm still alive, he's still alive, the children are good. Um, I just think its trials.

Tools

Caregivers utilized various tools to assist them in making caregiving easier with no marked difference between spouses and parents. Some used white boards and calendars to provide reminders to the veteran, others used durable medical equipment to

assist with activities of daily living. Some even contacted their congressional representative and/or senator to assist with concerns they were having with benefits and care for the veteran. Contacting a congressmen was the most popular tool used.

PG: We went all the way to the white house. The rating had been dragged out, dragged out, and yes I contact two senators and I call the white house. We were desperate. And I got a hold of the white house and I happened to get a hold of a white house staffer and that was on a Monday on a Saturday the VA called, on a Saturday and they moved his application to the top of the pile.

Texting was also a tool that was used to communicate with the veteran to help with reminders, and also to help diffuse emotional situations.

SG: No it's helpful, because sometimes there's things that he can't say to me and there's things that I can't say to him...He cannot take it when I cry. So if he wants to talk about a memory that hurts me, that devastates, me, it's hard for me to control my emotions...so it's easier for him to share that moment of what he's thinking by texting me and its easier for me to text him back more positively and he can't see my face.

Some caregivers even used phone apps to help with PTSD symptoms:

SG: ...we were at the naval hospital with (service dog)...one man, he was there with his wife...her husband went up to the front desk and asked if dog could be removed, my husband heard that (laughing)...and oh it was horrible. He started arguing with the man in the, I'm like lord please don't let these fools call the MP's cause I didn't want my husband to get in trouble...so I was like "(veteran name) let's leave", I had to use an app to calm my husband down....PTSD coach helped and I opened it up...the app pretty much moved on its own without that, you know, let's look at your anger, how you feeling right now? Well you know, what would you like to do right now, I mean I was just trying to, I was just going through it with him, and I...was pleasantly surprised, He was looking at it. He was actually moving some things around and engaging in it and I was like OK, this is good. You know so, apps help.

Hope

Many caregivers still retained hope that the situation would improve and the veteran would get better. Overall 10 caregivers spoke of how they still expected their

loved one to recover. There was no difference between spouses' and parents' perceptions of hope. One spouse, despite all the negative setbacks her husband experienced stated: "I don't think that it's gonna be like this forever. I don't think so". A parent (PG) spoke of concerns about their son's future and how they were hoping that he would be able to find someone to be with him and support him:

PG: ...my biggest hope is that he find somebody, because he is still young, that he is compatible with that can deal with the PTSD...his primary doctor told us...he will always have PTSD. He said that never goes away, it's the medications you take, how you take them, how you deal or learn to deal with situations is how you will function in life and I'm hoping that with us being here to give him this time to do all of that that eventually he will be able to find somebody and move out on his own. I don't think he will ever be able to live out on his own.

Although some caregivers maintained hope, five participants had lost hope in the veteran recovering and being able to resign the caregiving role. They felt it would be a lifetime commitment. A spouse (SG) spoke of how her husband's condition is worsening and how she feels even more isolated:

SG: It's not gonna get good, its gonna get worst and worst and worst and past three years he's gonna get worst, what next you know what's next. Now he don't wants to go out with me sometimes, not that sometimes he wants to sleep alone by himself. Sometimes um, he want to stay by himself in the house.

Uncertainty

Caregivers tended to experience uncertainty about caregiving and uncertainty about the future. Ten caregivers, both spouses and parents, spoke of these feelings in their interviews. One spouse described how the situation changed daily with regards to the veteran's behaviors and she was unsure how to cope with it ... "Because I think it will always be a challenge because you never know what's coming to you the next day you know?" Parents discussed their views about the future and caregiving:

PG...sometimes, you have to ask yourself, can I do twenty years of this? Well, I would hope I wouldn't have to

PG: Well and the days gonna come, were not gonna be around anymore, so he needs to learn how either take care of himself, he can take care of a lot of stuff himself, when it comes to mental things, making decisions, and financial and all that, he needs to have someone in place that he can turn to for things like that.

Guilt

Guilt also was a common emotion felt by the caregivers. Spouses tended to feel more guilt than parents, with only one parent reporting feeling guilt. One spouse was crying when she was asked if there was anything she felt guilty about: “He joined the military because of me (SG).” Another spouse talked about how she felt guilt when she did try to practice self-care “When I go to do something for myself, yeah. When I do something for myself because I am so used to putting their needs and wants first (CG).” Another spouse spoke of how she thought that things would be easier if she left her spouse, but then felt guilt about thinking this “... please just let me wake up and not love him anymore so I can feel better about leaving, you know (SG).” The one parent who felt guilt mentioned that it surrounded the fact that she did not realize the extent of his injuries and wished she had reached out sooner to help her son. Rather she believed him when he would boast and tell her that he was ok:

PG: I didn't know what I dealing with at all, I would have done things a lot differently because I think that maybe I hindered him getting help...I knew he was depressed. I knew that he wasn't the same person, but I think that I overlooked the way he was because I knew what his goals were and where he wanted to be and how he wanted his father to be proud of him.

Leash syndrome

Many caregivers found it very difficult to leave the veteran alone or if they did, they felt pressure to return home quickly, or to remain in close distance to the veteran to

be able to assist and/or provide care. There were 11 caregivers who described a leash syndrome. Spouses felt this more so than parents. One spouse spoke of how she is very cautious when she leaves her veteran at home:

CG: ...he's a grown man, let's be real, he can be here by himself, but it's not the best idea, for him to be here by himself because then it's like he gets you know, idle hands for the devils play, especially when he constant stream of so and so got blown up...So I don't, nothing limits me, but his injuries limit me in the sense that his injuries also limit him.

Another spouse spoke of how she was trying lift a friend's spirits who was diagnosed with cancer but she felt pressured because she was constantly texted or called by the veteran while she was with this friend. One parent discussed how they had to restrict their travels as a direct result of caregiving:

PG: Uh nothing no catastrophes or anything for leaving him for that long, but we can't make any long trips, we just, unless we take him with us, we just can't.

There were two other themes (service dogs/pets and military caregivers) that arose that are worth noting as they were unique factors to this population, although not shared as a common experience.

Service dogs/pets

There were a total of eight caregivers, the majority being spouses, who mentioned how valuable their pets/service dogs were for both the veterans' and caregivers' mood and health.

SG: He has his service dog...she really helped him to be able to get out and go different place especially like when's it crowded whatever. He's there for him. She brings him his braces. He'll get mad and throw his brace across the room, I don't wanna wear it, and she'll bring it back to him and he knows to put it on. So she's done great. I've got me a dog now. And to me she's like emotional support cause when I get upset, I'll put her up on

the little ottoman by my chair and just love on her and everything so. Animals are great.

SG: ...but when Vet is having anxiety of anything like that, his dog, is glued to him, or when Vet passed out, he passes out for a couple of days at time, he will sleep in the bed with him, pressed up against him. Um, he always has to have some sort of physical contact with him when he's having issues, so he has a sense of the mood so.

Military caregivers

There were two caregivers who served alongside the veteran or had “boots on the ground”; these caregivers seemed to understand the emotional and cognitive challenges much better than those who did not. As one spouse stated:

CG: ...think it's different for us because I actually served in the military, so you know, when you walk along side of your spouse, wearing the boots, I think it makes you a little more empathetic of survival skills and you know trying your best to keep alive, you know. So I think it's a little bit different for us. I mean he will talk to me, and it's a rarity that he shuts me out, you know he will talk to me cause he knows I've been through it with him.

Another spouse spoke of how she was able to advocate and navigate the system:

SG: It's helped because I can kind of understand, you've got to ask questions, you've got to push for answers. If you don't like the answer you get, maybe you need to ask the question a different way or ask someone else...acronyms they use are easier.

Qualitative research question 2

How have the caregiving experiences changed before the caregiver support program services vs. after receiving services? Are there differences between the changes for spouses and parents? All participants were asked about the impact of the caregiver program, specifically, what was working and what could have been better. They were also asked if the stipend was beneficial and if it alleviated any stress, strain, or concerns,

why or why not? All participants responded to these questions. There were four major themes (see table 4.7) that emerged with several subthemes.

Table 4.7: Research Question 2: Major Themes

Theme	<i>n</i>
Supportive Programming	<i>n</i> =15
Program Needs Improvement	<i>n</i> =13
Stipend Beneficial	<i>n</i> =13
Stipend Concerns	<i>n</i> =4

Supportive programming

The caregiver support programming provides a variety of services to the caregivers. All except one parent commented about the support services that are available to them and how they enjoyed either participating in the program or knowing it was available to them. Supportive services/programming that was mentioned included: the caregiver focus of the program, the classes, the advocacy provided by the program, the 24/7 support line, the home visits, the insurance offered, the counseling available to caregivers, and the mentoring. The caregiver focus of the program was something that was appreciated by eleven parental and spousal caregivers. One spouse spoke of how caregiving was a new role and how the program assisted her:

SG: Well definitely what has been helpful has been the caregiver support program, knowing how to support (veteran's name), knowing how to help him, is I mean you know. I wasn't trained on being a caregiver you know professionally, professionally my training was in education (laughing), so I mean you know, this um caregiving's new.

A parent spoke of how the program was helpful when the veteran returned and the mother did not know where to turn for support:

PG: Well, you know that I'm must have called in the beginning like a 100 times; you're always supportive. I always talk good about you and (case manager name), wonderful people, um. I love the program, the only thing I wish that would happen is that everybody can come together and be on the same sheet of

music.

Nine caregivers, mostly spouses, spoke of how they enjoyed the classes offered through the caregiver support program. One spouse discussed how the classes offered by the program impacted her, even though she sat back throughout the classes, she was absorbing all of it “Um we have, meetings with other caregivers, I may not say a whole lot, I enjoy every meeting that I’ve been to, every last one there are people in there that know how I feel” (SG). Another spouse spoke of the caregiver support department at the VHA:

CG: The development of your department. Creating that department, it gives caregivers, women like myself, the opportunity to um have resources and that would help us understand what the situation is, what to expect, what we’re going through how we can seek and get information elsewhere, um, how can it get better?

Five spouses, with the majority spouses with children (4) spoke of how the program was able to advocate for them and the veteran they were caring for:

SG: Well one of things that’s working well and has impacted our family is having a logical sequential order, is knowing the things that I know now, where to call, and who to email, and I’m not sure about something or where to get help... whether you can answer the question or not, having directional support knowing where to go, not being stuck saying ohhh being a in frenzy.

The 24/7 caregiver support line was also a resource that was noted by three caregivers, two of whom were parents. One of the parents stated that “I call the hotline to just to talk to somebody, to have someone to talk to, put into perspective is it me am I going crazy.” Two of the spouses discussed how they enjoyed the home visits with the program. Three spouses talked about how they benefited from one of the following resources: the counseling offered through the program, health insurance, and being assigned a peer mentor.

Program improvements

When asked about how the program could be improved, 13 caregivers discussed certain aspects that they felt were lacking within the program. These areas included: the lack of adequate staffing, the lack of support groups, the cumbersome application process, the inconsistency of delivery of services based on geographic location, not being aware of the program earlier, not needing home visits, more classes to help children adjust, difficulty with the online training that is mandated, the need for respite during trainings, and having more time for the classes. There was no identifiable differences with respect to spouses and parents, all equally presented suggestions. The lack of adequate staffing was the most prevalent theme with eight caregivers commenting on this:

CG: ...but the caregiver department widening in terms of ok we are in a rural area, your office your staff is very limited to how many people they can assist based on the geographic region that you have. How can they help? Hire more people...because believe it or not, when your staff come out once a year, it's a delight to have someone that's on your side. You know, um, that is coming with information, that's coming to help you, that asking you what you need. It's about you, it's not about the vet. ...you never know which women will be the women that you save.

Given the large geographic area covered by the NFSG/VHA, many caregivers (6) commented on the lack of local support groups:

PG: You guys are doing wonderful, maybe give you more resources. I don't know what the funds are like, I don't know how much they cut, but I know that funds always get cut, but um maybe have support groups in this county.

Two spouses commented on the inconsistency of how the program was delivered in different areas:

CG: Talking to other spouses it seems like there is a break down. It depends on what area you are in, as to what tier you're going to fall into, how quickly you can get the application in, get approved, training done and all that stuff. Things like you know, our areas is great, but if you go to I don't wanna say

a bigger area, but maybe that's what it is like in Texas or around a big army base or something like that, they just seem to struggle with it a whole lot more.

Some spouses (3) felt that the actual application process was cumbersome. One remarked on how she felt that there was little communication at the beginning of the program when she applied... “like I said from when I first came in at the beginning was real slow. Sometimes I thought you didn't even exist, like she's not answering me, where is she.” (SG) Another mentioned how other people she has spoken to commented how the process was difficult:

CG: I've talked to people who have you know, they've said well I've applied for this and I've been told oh we're backlogged, we don't have the people to come out, its gonna take a little while and they get frustrated or the people that say well why do you get rated at this tier where I only get this tier.

Two spouses commented on how they wished they would have known about the program earlier as it made a significant impact in their lives:

CG: I think a lot of my frustration initially like I had said was that I would have qualified for the CG program 3 years before I was actually on it...because that um it would have been at the time, had I been able to get into the program, life changing.

One spouse commented on how he/she felt the home visits were not necessary... “And for me we're not that bad off where we feel like you guys need to come out all the time” (CG). Another spouse wished that the classes incorporated some aspect of education about children who are living in the home... “if you could have something for them a program too, you know the classes for us, but with some activities. It's hard on the kids, like it was hard on my daughter” (SG). Another spouse commented on how she wished there was more time in the classes presented as there was so much information in a

session. One parent wished there was respite offered so the caregiver could attend the classes:

“It would be nice if they had a program where I could take him with me. You know and then that way, he can, as I’m relaxing and doing something for me, and maybe he can have something and they’ll do for him and even though he’s not with me, he’s still there.”

Another parent spoke of how challenging on the online training was to become approved for the program as he experienced many technical difficulties.

Stipend beneficial

Thirteen caregivers talked about how the stipend alleviated stress, strain, or worries that they experienced prior to receiving the stipend.

One spouse discussed how essential the stipend was to maintaining everyday basic needs while two spousal caregivers with children discussed how the stipend has allowed them to maintain employment by allowing one of them the opportunity to maintain daycare.

Another spoke of how the stipend helped her to work towards reducing her work hours.

Stipend concerns

Despite the positives of receiving the stipend, there were four participants (three spouses, one parent) who noted concerns about the stipend. One male spousal caregiver spoke of how he felt like less of a man for receiving it and his concerns about losing the stipend:

CG: I do feel guilty and I’ve told her, I’ve actually wanted to tell her I don’t wanna do the caregiver program anymore because I don’t want to have to worry about it being taken from me you know. I just, to me, it feels like a threat sometimes. Like it hangs over my head. And I don’t want it to be that way, but at the same time I need it. I don’t feel like I should be getting wage to take care of my family but at the same time I feel like I do need a wage because I can’t go to work.

Another spouse also spoke of the fear of losing the stipend: “So if the stipend goes away I don’t know what would happen to us right now and I’m being honest” (CG). A parent discussed how she was doing well financially and did not really need the stipend.

Another spouse discussed how it was not enough: “No because you’d always like it to be a little more money (CG).”

Qualitative research question 3

How does having children affect the spousal caregiving experiences? All the spouses were asked how having children in the home effected caregiving. Table 4.8 represents the themes and subthemes that were reported.

Table 4.8: Research Question 3: Major Themes and Subthemes

Major Theme	Subtheme
Negative Outcomes	Child behavioral changes Caregiver as a buffer between children and veteran Loss of time with children Children witnessing dysfunction Veteran caring for children (negative) Encouraging veteran to engage with children Sole parent for children Hoping children do not date/marry anyone from the military Caregiving easier without the children Not having children due to injury
Positive Outcomes	Children giving the veteran purpose Veteran caring for children Children giving the caregiver purpose Children learning about mental illness Children studying medical field

Negative outcomes

There were far more negative consequences that were observed and felt by the children in the home than positives. There were almost three times as many negative references as there were positive within the interviews.

Behavioral changes: Behavioral changes was the most referenced outcome that was seen with the children. The biggest behavioral change was seeing the children within five families acting in a caregiving role:

CG: ...but I can see differences in them compared to their friends. (Child's name) is a very mature 8 year old, she likes to take care of everybody. Sometimes, I rely on her to do things and I probably shouldn't, because I feel like I'm making her grow up faster than she needs to, but at the same token, she wants to help, um...She'll go ok, I'm done cuddling with mommy, (child's name) you come cuddle with mommy and I'll come sit with dad. And so she'll go and sit in his lap and she'll sit there still as a stone and just cuddle with him while we watch a movie or something.

The second biggest behavioral change observed was the children detaching from the veteran. One spouse spoke of how when her children left the home for college, they would call and rather than referring to their father as dad, or daddy, they referred to him as her husband. One spouse spoke of how her children pulled away from their father as he could not tolerate their normal behaviors. Another spoke of how her daughter became more reclusive and spent less time with the family by isolating within her room.

There were two spouses who spoke of how their children became fearful of the veteran based on his reactions to situations and behaviors in the home. One spouse discussed how the veteran was harsh with discipline due to his inability to regulate emotions and her daughter became fearful: "the daughter getting scared and backing into the corner because of it, so it affected a lot of stuff." Another spouse spoke of how she

had to remove herself and her infant son from the home after the veteran became upset. She sought shelter at a local hotel for the night.

Two caregivers spoke of how their children would manipulate the injured veteran so they could get what they wanted. One described a situation in which the child took advantage of the fact that the veteran had a brain injury:

SG: ...quickly dad has issues memory issues or what have you, he learned to manipulate the situation and we went through, he would like, he would steal sneak out of the house and as much as we love him, he tried the patience and it was always oh well dad said I could do this. If I went to work and I knew, I would leave like \$5 or something and if it went missing, "oh dad must have spent it" that type of thing so, it got hard because then trying to discipline them

Another behavioral change that was noted by one spouse was a child who began to blame the caregiver for not being understanding and patient with the veteran:

SG: And she said, mom, he has PTSD and all those other problems. It's not his fault, you deal with it. And I thought, so much for support. Her father can do no wrong and I just have to you know deal with it. I was shocked. There's no point you know.

Another spouse discussed how her two children's behavior changed and they started to emulate the veteran's behaviors in social situations by isolating themselves and watching others from a distance.

Caregiver in a buffering role: The next most referenced negative outcome was where the caregiver acted as a buffer between the children and veteran. Buffering included setting boundaries and protecting the children from the veteran when the veteran became agitated or overly frustrated. Spouses with children (SG) spoke of the many ways they protected their children and set clear boundaries:

CG...listen, I'm not gonna put up with your crap anymore. You know, fix it or, were, we are gonna have a serious discussion because you know momma

bear has to protect the cub.

One spouse talked about how she had to hide the veteran's drug use from her daughter:

CG: And it's not something where you want to walk up to your kid and say well here, you daddy went out and he smoked \$10 worth of crack.

A wife described how she would protect and buffer the veteran from others when they were out in public or family situations as he had a tendency to be rude to other. Another described how she thinks she would have left the veteran if he would have escalated to a point where he was abusive to the children. This was a boundary that the veteran would not be allowed to cross.

Lack of time with children: Caregiving can be very demanding and not surprisingly, many spouses spoke of how they are or were unable to spend as much time with their children as a result of caring for the veteran:

SG: It's like a few days you know that I tell them that I'm cooking something for dinner and to come by I do miss them. I miss the grandchildren, I miss see we had 6 children and so the house is like empty, so I miss you know the noise you know.

CG: I've gotta constantly be aware of my wife's situation it takes my time and focus off my children, so I feel some of the attention I give my wife I should give to my children. It's a constant juggling act.

Children witnessing dysfunctional behavior: While most of the spouses tried to protect their children from seeing the veteran's dysfunctional behavior, three were unable to:

CG: They really disliked him, uh a whole lot. And with one of the twins their relationships has changed more than any other of the children. And sometimes she can go without telling him that she loves him for days. Um, he he, sometimes he can say some strong words and she doesn't like him you know. She loves him I know, but she dislikes him a whole lot, yeah.

Veteran as a caregiver (negative): Some caregivers discussed how the veteran had to care for their children and how this resulted in some challenging situations. One

recalled calling the veteran to check on him and their baby. The veteran complained that the baby would not stop crying, only to discover that he had forgotten to feed her. From that day forward she had to call to remind him to take care of the baby's basic needs.

Encouraging veteran to engage with children: One caregiver talked about how she had to encourage the veteran to partake in activities and specifically foster his relationship with their children:

CG: Getting him out of the fog and trying to keep him basically like you would say in the land of the living where, you know ok, come out the bedroom, stop isolating yourself in the garage, you need to come in here and even if it's just being on the couch and watching a movie with me and kids, let's do it.

Sole parent to child: One caregiver spouse of how she was the only one that was able to provide care to the children they shared:

CG: I take care of the baby solely on my own because you know, he loves the baby, he's a good dad, but there is there is a little bit of disconnect there um because of things you know that he's had to do on deployments.

Hoping children do not date someone from the military: One spouse spoke of how thankful she was that her daughter was no longer dating a man that was in the military. She did not want to see her daughter experience the transitions she has had to endure.

Not having children due to injury: One caregiver spoke about how she always pictured her future being with a family and children. Ever since the injury, she has decided against this. She goes one to state that: "It wouldn't even be fair to bring another child into I don't think." She refers to the veteran as a child in this quote.

Positive outcomes

All of the spouses who raised children or were currently raising children were able to identify positive aspects of having children in the home while they cared for the

injured veteran. One of the most common subthemes was how the children gave the veteran a sense of purpose. Having come back from the military injured diminished dreams and hopes for most of the veterans, but having children and being responsible for them, provided them with a new purpose upon their return. One spouse spoke of how having a newborn was a type of physical therapy for the veteran upon his return post injury as he was unable to be idle. Another spouse spoke of how the interactions with her daughter helped the veteran learn positive communication skills. Another described how their baby's laugh was so inviting and infectious.

Other spouses described how the veteran was able to be a caregiver to their children despite needing a caregiver for their own needs. One spouse spoke of how the veteran cared for their young baby on his own, but she was never too far out of reach:

CG: ...They don't you know stay by themselves but he'll feed him dinner or I'll tell him hey you know, go for a quick walk around the block, leave him in his high chair you know he'll feed him dinner, he'll bathe him but I'm in there showering at the same time. He will get him dressed in his little pajamies and things like that.

Another described how she was not a morning person and the veteran took care of their daughter while she rested. Four of the six spouses without children described how it was easier to care for the veteran without the children in the home:

SG: Well at least I don't have to worry about doing everything you know to, to guide her and everything. That's one less thing I have to do. Um, yeah not having the kids actually is easier, one less person to make a mess (laughing) and take care of.

Another described how it was not necessarily the children that made it harder for the caregiver, but the burden it placed on the injured veteran to interact with the children.

Three spouses spoke of how having the children in the home gave the caregiver a sense of purpose:

SG: I think with the girls being gone and when they come home I love it when they come home. I feel a little bit better when they come home even though he took up a lot of my time, I was still forced to focus, not just on him but on other things. On them, hopefully I did.

Three spouses discussed how their children were able to see how mental illness presented itself. They felt it was a good experience for the children:

SG: I want to say, my grandson and my daughters see firsthand what can happen. Not the injuries that you can see but the mental injuries.

One spouse talked about how her daughter decided her career path based on the veteran's injuries: "Well for one thing, she decided to go into the medical field (SG)."

Qualitative research question 4

What is the role of online support community (e.g., social media, blogging) in caregiving experiences? Are there differences in the role of online support between spousal caregivers and parental caregivers? All 16 participants commented on the role of online resources and technology in caregiving. Participants were asked how the internet effected caregiving and if they thought that technology was isolating or if it brought people closer together. Table 4.9 represents the themes and subthemes that were reported.

Table 4.9: Research Question 4: Major Themes and Subthemes

Positive Outcomes:	Online support Internet as a search tool Technology bringing support close Utilizing VHA my healthy vet Utilizing internet for self-care Texting as a strategy for caregiving
Negative Outcomes:	Mistrust in online support Technology isolating

Positive outcomes

All of the caregivers commented on positive aspects of utilizing online support and technology to assist them with caregiving.

Online Support: The most popular usage was to get online and seek out support either through Facebook groups or other caregivers' support groups. Ten caregivers (8 spouses and two parents) utilized this methodology. One parent spoke of a group that was specific to veterans with invisible injuries and her experience with the group:

PG: ...On Facebook they have a forum there for uh the ones with the invisible wounds...it's nice to have social media where you can pick and choose who you want to talk to. Most of the time you go into the invisible wounds because um, these people can relate to you in same way that you are. They can actually help you. Or it can be the actual veteran saying well if he did this, it's probably because of this and you go, really? I never thought of that, so when it comes to the actual veteran, so yeah I love it.

Another spouse spoke about how she started her own blog of her own experiences in caregiving:

CG: I have 40 or 50 women and men who get my posts via email and um, I have gotten emails in the middle of the night from people before and so I try to be vigilant about answering those kinds of things because we're all in this together kind of thing.

Another spouse said how it was so much easier to share online then in person as there was a sense of anonymity.

Internet as a search tool: Many of the caregivers talked about how they researched their loved ones' injuries online by searching for PTSD etc. There was a notable difference between spouses (6) and parents (2) with spouse's utilizing the internet more often. One spouse described how efficient and effective the internet can be:

SG: Technology has helped with finding that information so that I can advocate for my husband, congressional letters, I've been able to do them online. I have not needed to do just, nothing wrong with just typing out and mailing, but I've been able to do it quickly and get it to them quickly and

they respond quickly back to me. Email too, I've been able to send messages quick. Technology has played a huge role in caregiving and in advocating and in finding information out and in networking.

Another spouse spoke of using the internet to search information on PTSD, substance abuse, and research articles on various topics. One spouse just commented "I've used google quite a bit."

Technology bringing support closer: Seven caregivers, all spouses, spoke of how technology was able to bring them closer to their friends and families and made them feel less isolated.

CG: One of the worst thing of being a caregiver is that very often you very isolated. If you cannot see people you know in person, it's important to be able to reach out to someone somehow, so on the phone or through those sites.

Using the VHA my healthy vet: One parent and three spouses all discussed how they used the VHA's online medical benefits system to access the veteran's healthcare information, re-order medications, and email the treatment team:

PG: The secure messaging is really easy, I can communicate with his doctors you know, if I have to drop him off for an appointment I need to come back and get him, I can communicate with them ahead of time

SG: Um, the only the thing that I guess makes it easier...being able to order his meds on line and have them sent to the house and not having to run around to get those, cause we run around enough.

Online for self-care: There were three spouses who used online resources for self-care:

CG: Yes, I do Instagram, Facebook and twitter and its great stuff for I think for stress relieving cause there are great options for, even Pinterest, DIY stuff and you know having the warmer weather makes it fun. Stuff like going out and painting and stuff and finding different stuff to do. Um and there's always great recipes and stuff like that that are quick only a couple of ingredients I can stick in while I'm cleaning or doing homework of whatever, so

Texting as a strategy: Five caregivers mentioned how they have used texting to assist in providing care. One of the five was a parent who described how she would text her son/injured veteran to communicate with him even when they were in the home together. A spouse talked about she was able to talk with her husband to resolve disputes through the use of texts:

CG: I still look at my husband every day and forget. It all got started because I sent him a text message I said, I owe you an apology, cause he was in class, I owe you an apology, what are you talking about what part, I said I forget that you have those issues and it was just at random...I told him, we've had conversations via text message but the gist of it was I forget and sometimes I expect, I look at him and I expect him to react a certain way. Cause the guy over there reacts that way and (friends name) husband reacts that way, why can't my husband react that way you know.

Another spouse spoke of how she texted the veteran to remind of things as his TBI caused him to forget to look at the lists she would usually send with him.

Even though many caregivers had positive comments about being connected, there were some who did have negative experiences. Nine caregivers spoke of some of the troubling aspects.

Negative outcomes

Mistrust in online support: Some caregivers did not feel comfortable sharing their information online as they felt that they led private lives and did not want other people who they did not know to be involved in their private lives:

CG: I mean, you can't believe you hear on the internet of course, I think that's a big negative, you know, because you read these things and your like oh yeah and then you find out its all bologna, so I would say that's a negative, but you know also to go along with that, it's kinda hard to put your business out there. So that's why when I was at my wits end, I was like please keep this anonymous you know so that's tough too trusting people that you don't know.

One spouse simply stated: “No no no, I don’t trust that, I don’t trust that (laughing).”

Technology isolating: Caregivers are able to reach many people with the World Wide Web and texting, however, some people feel this cannot replace the support achieved through personal contact. Six caregivers, one parent and five spouses, all shared this thought. One parent shared how her son/injured veteran was unavailable as a result of technology:

PG: I think it isolates because I think vet does a lot of that uh when he’s barricaded in his bedroom. I think he spends more time on well whatever. And I don’t know is its internet, Facebook whatever he’s on, but I think that takes away time from us not necessarily we would be doing anything, but I still think it does. It isolates people, I don’t think it is a help, I never have.

Several spouses shared their concerns and mixed feelings:

SG: You know it sickens me to go anywhere, it sickens, I mean it really does to go anywhere and see people like this all the time (head in phone making texting gesture). The person next to you could be choking getting a heart attack and you’re just...(uses hands to simulate texting on a cell phone)

Summary

Study results demonstrate some distinctive findings to include significantly higher ZBI scores for caregivers with children in the home compared to those without children and spousal caregivers when compared to parental caregivers. Caregivers’ shared experiences resulted in 22 major themes which included family adjustment, subjective demands, coping techniques, social support, Veterans Affairs (VA) and Department of Defense (DOD) services, self-care, intimacy, role strain, financial resources, and life course changes as the most prevalent. Caregivers and their families, especially spousal caregivers, had a difficult time adjusting post injury, particularly with subjective demands. Caregivers relied mainly on their own coping mechanisms to adapt to their new role and did not find social support to be beneficial with caregiving. While the

Caregiver Support Program provided many services that were helpful to the caregivers, including a financial stipend, the caregivers overall wanted more financial assistance and support services and reported concerns with program implementation and staffing as major barriers to effective program implementation. Children tended to add complexity to the caregiving relationship and also increased burden. They displayed behavioral changes, mostly negative, but also did have some positive impact on both the caregiver and veteran. Lastly, technology and online support with caregiving was used more often than not with mixed feelings about the technology and its trustworthiness; with parents not utilizing these resources as much as spousal caregivers.

CHAPTER 5: DISCUSSION

This chapter summarizes the quantitative findings and qualitative synthesis that describes the overall experiences of caregivers and relates the study findings to the stress and coping theory and the stress process model. The chapter also describes how the research findings contribute to the field with the limited literature available. The chapter concludes with implications for social work practice and research, recommendations for future research and practice, and limitations and strengths of the dissertation study.

The purpose of the dissertation study was to explore how demographic characteristics, having children, stipend/tier levels, and diagnoses impact levels of caregiver burden; and to explore caregivers' perceptions about caregiver burden for caregivers of veterans enrolled in the Caregiver Support Program within North Florida and South Georgia. The study used mixed methods which included a secondary quantitative analysis of recorded data with 172 participants in the program and in-depth qualitative interviews with 16 participants that explored caregivers' lived experiences of caring for a seriously injured veteran. Themes were derived from the in-depth interviews with additional focus on how children impact caregiving, the effects of social media on caregiving, the impact of the Caregiver Support Program (CSP) on caregiving, and parents versus spousal experiences with caregiving.

Stress and Coping Theory and Stress Process Model

This study used the stress and coping theory to understand the transition that an individual experiences in light of a stressor/traumatic injury which results in either the

successful or unsuccessful adaptation to becoming a caregiver (Lazarus & Folkman, 1984). All these caregivers faced a period of family adjustment which was the most prevalent theme experienced by all the caregivers. The stress process model allows one to understand the life course and how unexpected changes in the lifespan, as experienced by all of these individuals, resulted in consequences in many areas of their lives (Pearlin, 2010), particularly in the lives of caregivers who care for children in addition to the veteran. Not only did the caregivers' life course significantly change in terms of dreams, hopes, family dynamics, finances, goals, and health, but caregivers also reported changes with their children with respect to behaviors, roles, and social development. In essence, there was a snowball effect starting with the veteran's invisible injuries, and resulting in impacts in many different realms of the caregiver's lives.

As stated in the literature review, three mediating factors were associated with a successful adaptation to caregiving which included social support, coping mechanisms, and caregiver resources (Dow & McDonald, 2003; Lazarus & Folkman, 1984; Monahan & Hooker, 1997; Pearlin, 2010; Savundranayagam & Montgomery, 2010; Zarit & Zarit, 2007). Mediating factors were discussed by all the caregivers. In this population, positive coping techniques were used twice as many times as negative coping techniques to adapt to the new role. The provision of social support was not utilized or as helpful with this population as the caregivers reported more negative experiences with social support networks. Negative experiences included social undermining when utilizing social support, as well as a stigma associated with having an invisible injury, specifically where the caregiver and/or veteran's support network were unable to recognize or acknowledge the veteran's needs. This supports previous studies with families of a

veteran suffering from PTSD (Jakupcak et al., 2010; Jordan et al., 1992; Ray & Vanstone, 2009) and is further corroborated with post 9/11 military caregivers, as approximately 53% reported not having a support system to assist with caregiving (Ramchand et al., 2014). The theoretical framework suggests that the mediating variables result in either a successful adaptation to caregiving or a situation where the caregiver experiences caregiver stress. For 32% of the sample, caregiving resulted in stress, with spouses experiencing more strain than parents.

Discussion of Demographic and Contextual Factors

The average age of caregivers in this study was 39 years of age, which is comparable to other post 9/11 caregiver studies reporting the average age as 38 (Tanielian et al., 2013). Females were the majority of caregivers (94 %) which is similar to previous VCG at 96% (NAC, 2010), but contradicts a recent study which suggested that 40% of post 9/11 caregivers were male (Ramchand et al., 2014). The majority of caregivers (80%) were spouses which is higher than other post 9/11 (33%), pre 9/11 caregivers (22%) and civilian populations (16%) (Ramchand et al., 2014). There were 81% of caregivers who were caring for veterans with PTSD in this study versus post 9/11 (52%), pre 9/11 (18%), and civilian caregiver populations (8%) (Ramchand et al., 2014). Demographic variables (race, age, and sex) did not result in any significant differences in levels of caregiver burden in this study.

The average amount of time the qualitative sample of caregivers had provided care was eight years, with spouses providing an average of nine years, and parents an average of six years. When compared to the other groups of caregivers whose average is 4.8 years of care (NAC, 2010), these caregivers already supersede other caregiver groups

and confirm initial speculation that they would be providing care for longer periods of time (Tanielian et al., 2013). However, Ramchand et al. (2014) compared post 9/11, pre 9/11, and civilian caregiver's length of time providing care, and did not find any differences between the groups. This may be indicative of the severity of injuries with this group of caregivers, versus those in the aforementioned study. Of note, the caregivers in this sample were still actively providing care, therefore the numbers are not representative of the total amount of years of care provided; the total duration could be significantly higher.

Financial burden was a common theme in this population, however, this population of caregivers was unique in that they were all receiving a financial stipend. Presumably, financial burden was somewhat alleviated as a result of the stipend, however ten of the caregivers interviewed (62%) reported still experiencing financial burden. This finding mirrors the percent of VCG's who reported financial burden as reported by Griffin et al. (2012), so one could speculate that even with a stipend, financial concerns remain a prominent theme.

Discussion of Quantitative Hypotheses

Hypothesis a

It was hypothesized that men would have lower levels of caregiver strain. The hypothesis that men would have lower levels of burden was not supported as reported in other caregiver studies by Zarit and Zarit (2007) and Navaie-Waliser et al. (2002). There was essentially no difference between gender and burden. Findings of the present study support previous findings with caregivers who provided support to Vietnamese veterans

with PTSD suggesting that demographic variables did not have a moderating effect on caregiver burden (Beckham et al., 1996; Calhoun et al., 2002).

Hypothesis b

Spousal caregivers would have higher levels of caregiver strain than parental caregivers. This hypothesis was supported with both quantitative and qualitative findings. Spousal caregivers were affected by significantly higher levels of caregiver burden compared with parent caregivers. This finding may reflect role strain, as supported by qualitative results, experienced by spousal caregivers who were attempting to raise children, take care of the veterans' care needs, and also manage the household at the same time. Also parents have at some point in their life been in a caregiver role to their child, so the caregiving role is not new, but rather the role was not expected at this time in their life course. Adjustment to the role by parents was relatively easier as indicated in the qualitative results. Also spouses reported more difficulties with subjective demands, as opposed to parents, which also resembles outcomes in the literature (Beckham et al., 1996; Hayes et al., 2010; Jordan et al., 1992). This finding is also supported in other populations of caregivers where spouses do experience higher levels of burden (Ramchand et al., 2014; Gordon & Perrone, 2004; Verhaeghe et al., 2005). In one study, spouses experienced more strain than parents due to underutilization of services and resources (Zarit & Zarit, 2007); in the present study spouses had a harder time with using the community resources while parents were more successful.

Hypothesis c

Caregivers with children in the home would have higher levels of caregiver strain than those without children in the home. This hypothesis was supported by both

quantitative and qualitative findings; there was a significantly higher burden level with caregivers who have children in the home versus those that do not. This finding is significant because not only does it add new knowledge to the literature, but it also confirms Pemberton et al. (2013) speculation that children would contribute to higher burden levels when the parent was caring for an injured veteran. The finding suggests the need for services and interventions to be developed to assist not only the caregivers but the children. Qualitative results confirmed that children had a difficult time adjusting to the injured veteran in the home and caregivers were in a role where they were juggling multiple responsibilities and also attempting to protect the children from the maladaptive behaviors the veteran may be exhibiting. It is important to note that children did add some positive experiences which included giving a purpose to the caregiver and veteran, and assistance with caregiving which was supported in the literature (Hayes et al., 2010; Ramchand et al., 2014).

Hypothesis d

Caregivers caring for veterans with dual diagnoses would have higher levels of strain than those caring for veterans with a TBI or PTSD alone. This finding was not supported by the study findings. Diagnosis had no relationship to caregiver strain in the quantitative analysis. It might suggest that these injuries alone or together have an equal effect on the family system as both injuries have cognitive and psychological components to them which were characteristics that were reported to be more challenging for caregivers to manage in the qualitative study and in the literature (Beckham et al., 1996; Hayes et al., 2010; Jordan et al., 1992).

Hypothesis e

Caregivers being paid at the higher tier levels would have higher levels of strain.

This finding was not supported in the quantitative analysis. Even though Montgomery et al.(1985) suggest that higher levels of care result in higher levels of burden, there was no relationship between caregiver burden and tier level. In the Caregiver Support Program (CSP), there is an assumption that the caregiver provides more care based on the tier level. The inconsistencies in program implementation, as suggested in the qualitative study, may have some bearing on the accuracy of the tier level and therefore not truly reflect the amount of care provided.

Discussion of Qualitative Research Questions

Qualitative question 1

What are the lived experiences of spousal and parental caregivers of veterans returning from Iraq and Afghanistan? Are there differences between the lived experiences of spouses and parents? The results section provides the themes that emerged from the study in greater detail. Both types of caregivers while unique in many ways, share many commonalities with other caregivers. The stress process model postulates that caregiver's response to stressors (invisible injury) and secondary stressors (family adjustments, subjective demands) can be mediated by use of coping mechanisms, social support, and resources (Lazarus & Folkman, 1985; Pearlin, 2010). In this study, the caregivers primarily used coping mechanism to deal with their adjustment with limited use of social supports or community resources. They experienced family adjustments, dealt with subjective demands which proved to be very challenging, and

grappled with major changes within the life course which resulted in stress/strain rather than a successful adaptation to caregiving.

The family system was impacted primarily in negative ways, mostly as a result of the subjective demands, specifically the cognitive and psychological demands resulting from the PTSD and/or TBI. The family attempted to adapt by using humor, relying on traditions, creating new traditions, and ultimately finding a new normal. However, sometimes the family was unable to return to a homeostasis and it resulted in jealousy, issues with trust, lack of communication, veteran's loss of identity, isolation for the veteran, and the veteran being seen by the caregiver in a childlike role.

There was often a trial and error period in learning about the veteran and how to cope and adjust to the injuries. It was common for the veteran to be secretive or not disclose the injuries to the caregiver upon their return and caregivers were sometimes left in the dark without an understanding as to what was happening to their loved ones. In terms of family adjustment, spouses tended to have more negative experiences as opposed to parents and the former tended to not seek out social support or if they did, they encountered negative experiences so they shied away. Many caregivers felt the veterans' behaviors were not understood or minimized by friends and family, or the veteran pushed support away. This seemed to be directly related to the veteran suffering from invisible injuries (a disbelief in the injuries as reported by caregivers) or their own maladaptive behaviors which drove others away. Sometimes caregivers chose not to use social support because they did not think others would understand the veteran's injuries, which has been evidenced in the literature (Gordon & Perrone, 2004; Verhaeghe et al., 2005).

Caregivers struggled overall with navigating the VHA and DOD systems with spouses tending to struggle more with navigation. They were not provided an orientation and it was a struggle for most to access services or to be recognized since they were not a veteran. Many wanted some guidance and most reported struggles with getting compensation from the VHA.

Intimacy was also a major concern for spouses, particularly those who did not have children in the home. Many described the lack of touch, emotions, sexual intimacy, and a bond with the veteran they cared for. Some caregivers were not interested in being intimate as it was one more thing for them to do. Divorce rates are six times higher in couples when the spouse suffers from PTSD (Monson & Taft, 2005), which illustrates the need for interventions that are aimed at the couples.

On a positive note, this cohort of caregivers was aware of the importance of self-care and the need to practice it. This could be a result of the training all the caregivers completed in order to be approved for the program or ease of access to resources/education online, but nonetheless, they knew self-care was an important part of caregiving. Some practiced it in various forms including gardening, journaling, music, relaxation, etc. But others, even though they knew self-care to be important, still did not incorporate it. Spouses were more likely to engage in self-care than parents. In light of the finding that spouses experienced higher stress than parents, this seems logical. Parents may not feel the need to be as concerned with self-care because they were experiencing less stress. Pets and therapy dogs were also a positive aspect worth mentioning in this population. Whether the pet was trained or not, pets provided positive

support to the veteran and the caregiver as has been reported in previous studies (Shubert, 2012; Yount, Olmert, & Lee, 2012).

Another unexpected finding that bears some discussion is the caregiver who is also a veteran themselves. These caregivers were unique because they were able to truly understand the needs of the veteran and tended to not enable the veteran. As one caregiver stated she had “boots on the ground” and this was a major distinction in the way she coped with caring for the veteran. They were more likely to encourage the veteran and empower them. They also felt they were more equipped to deal with the demands of caregiving given the need to be resilient while in service and upon discharge. A recent study reported that 20% of post 9/11 caregivers are veterans themselves, a number that is higher when compared to other veteran and civilian caregiver groups (Ramchand et al., 2014) making these findings related to veteran caregivers experiences relevant.

In summary, what was unique about the spouses in this population was that they were younger on average than other veteran and civilian caregivers (Ramchand et al., 2014; Tanielian et al., 2013), some were caring for children in addition to the injured veteran, there was a considerable impact on the children in the home, they experienced and discussed concerns with intimacy, and despite the supports provided (CSP, VHA programs, community programs) they still reported a need for further support and resources. There is little research on young spousal caregivers who care for their partners (Tanielian et al., 2013); one might speculate that the timing and sequence of the events that ultimately led to them being caregivers may be an essential factor in the changes they endured. If the life course was closely examined, spousal caregivers would either be in

the midst of raising their children, or in a stage of empty nesting. Both stages are very significant and include a hope or vision that incorporates a healthy spouse that would assist in raising a family, and providing income and/or support. For the spouses who are younger and raising children, they have not been able to establish a career, or gave up their careers in order to provide care. While the stipend and services provided do give a sense of relief, it may not compare to the income and savings that the spouses could achieve through employment in order to plan for the future if they were active in the workforce. Also many of the spouses gave up educational goals as well as retirement plans in order to provide care which significantly alters their future life course. Some parents were using their own retirement savings to provide the veteran with assistance. They seemed to express much more relief from the stipend than did spouses. This may also reflect their stage of life. They have saved and for the majority of parents interviewed, they were retired. Most of the parents did not use the stipend to cover their own expenses, but to support the veteran and his/her own needs related to day to day living expenses.

An important difference was found between spousal caregivers and spousal caregivers with children in the home. Spousal caregivers without children utilized more maladaptive coping skills (including enabling), were less successful with utilizing social support, and also struggled with intimacy with the veteran when compared to their spousal counterparts who also cared for children; caregivers with children were found to have higher stress levels, but appeared to use positive coping techniques more effectively. It also seemed that they suffered more physical maladies from caregiver strain as well, suggesting that they might become overly immersed or enmeshed in caregiving, without

setting proper boundaries. A previous study with spousal caregivers caring for Vietnam Veterans with PTSD also reported that spouses moved through three phases including adjustment, enmeshment, and finally adaptation (Jordan et al., 1992), which might suggest that these spousal caregivers without children could possibly be working through the enmeshment stage of caregiving.

Qualitative question 2

How have the caregiving experiences changed before the caregiver support program services vs. after receiving services? Are there differences between the changes for spouses and parents? All the participants spoke about the CSP as all were enrolled. The majority of the participants discussed how they enjoyed the supportive programming and how beneficial the stipend was. Overall, this program was well received by the caregivers in terms of the supports and the stipend, with no identifiable differences between the spouses and parents. Only one parent spoke about how she did not need the stipend as she had adequate financial support. The others all expressed needing it, and some wanted more. Two spouses (13%) continued to work, but all the others were not working suggesting that the stipend may alleviate the need to work, in conjunction with the veteran's disability pay. Current estimates of post 9/11 caregivers depict that 76% of this population of caregivers are employed (Ramchand et al., 2014), however, Griffin et al. (2012) did report that post 9/11 caregivers caring for veterans with TBI's, were leaving the workforce to provide care. These contradictory findings call for the need for more in depth research specific to the stipend and its impact.

In terms of improvements to the program, there was no identifiable differences between spouse and parents. The caregivers overall wanted more of what was being

offered including more local supports and additional staffing in the program to increase accessibility to staff. They appreciated that there was a program that recognized the caregiver at the VHA and was available to assist and advocate for them at an organization that has been historically veteran centric. The CSP is unique in the comprehensive services it provides to caregivers. Despite the positives, some also expressed a need for more consistency in delivery of the program across the nation and in tier levels. There were three caregivers who mentioned concerns about the stipend related to losing it, wanting more financial support, and feeling like less of a man for receiving it. Since there was only one male spouse who was interviewed, it is a noteworthy finding that he felt like “less of a man” for receiving it. This result should be further explored with male caregivers while examining gender differences in the role of caregiving as Ramchand et al. (2014) indicated that 40% of post 9/11 caregivers are males. Also since most of the caregivers (77%) are not working in this population, further exploration should be done to examine how and if the stipend is alleviating the need for employment.

Qualitative question 3

How does having children affect the spousal caregiving experiences? All of the spouses commented on this with the exception of one, who did not have any children. Those who did not have children in the home, commented on their experiences of when their children were in the home while they were providing caregiving. Some of the parent caregivers also commented on having grandchildren in the home. Parents seemed to report higher levels of stress when the children were in the home with the veterans as they were having to care not only for the veteran but for their children.

Spousal caregivers also mentioned the positive aspects of having children in the home, but the negatives heavily outweighed the positives. In most cases, children added complexity to the family relationship and resulted in higher stress for the caregiver. It seemed that children's exposure to the veterans' maladaptive behaviors resulted in behavioral changes in children; this phenomenon has been supported and speculated in the literature (Flake et al., 2009; Hayes et al., 2010; Pemberton et al., 2013; Ramchand et al., 2014). Surprisingly, many of the children emulated the caregivers' behaviors and tried to take on a caregiver role, even though caregivers tried to avoid this. Children also became fearful and avoidant of the veteran and the spousal caregivers spent time acting as a buffer between the children and the veteran, as well as setting boundaries with the veteran when it came to the children and discipline. This all suggests that the exposure to injured veterans with PTSD and/or TBI can result in some negative consequences for the children in the home and more education and resources might be beneficial. One caregiver utilized the stipend to assist with daycare costs so the children had the opportunity to socialize and remain there after school and in the mornings. Exploring the feasibility of subsidized daycare/afterschool care may serve two purposes, allowing the caregiver some respite, but also exposing the children to age appropriate activities and socialization while diminishing their exposure to maladaptive behaviors. Some positive aspects of caregiving included the children learning about mental illness and providing the veteran and caregiver a purpose post the injury.

Qualitative question 4

What is the role of online support community (e.g., social media, blogging) in caregiving experiences? Are there differences in the role of online support between

spousal caregivers and parental caregivers? Online resources, online support, and texting were utilized by a majority of the caregivers, but the parents were less likely to use them suggesting that they may need to be taught or that they may not be as comfortable as the spousal groups in using this medium. Spouses used blogging and Facebook groups more than parents to assist with caregiving. They were able to reach out to online groups for support in caregiving. Some even used the VHA online system to assist with caregiving, as they were able to order medications and email providers. Texting was also used to communicate with the veteran as a strategy to ease emotion from the conversation. A few participants were cautious about the use of technology citing mistrust in the medium and feeling their privacy would be violated. Some felt that the medium was unable to provide the face to face support that they were craving. Parental caregivers may need some guidance and education on how to utilize these supports or where to find them especially since 79% of caregivers today do have access to the internet (Fox & Brenner, 2012). While the CSP does provide an in person course through Easter Seals called “utilizing technology,” the lack of staffing and the lack of respite hinders the accessibility to these valuable programs. Caregivers tend to utilize the internet more so than other users, especially when it comes to accessing social tools that assist with health (Fox & Brenner, 2012) making it essential that alternative methods to traditional in person supports be more readily available to caregivers (Sayer et al., 2010).

Implications for Social Work Practice and Research

This population of caregivers is very unique and social workers within the VHA system and community settings are ideally situated to provide support, resources, and intervention for this very vulnerable population. In clinical practice social workers

should incorporate questions that focus on the themes identified in this study with particular attention being paid to the family system and how it adapts to the returning veteran. Education should be provided to families about what to expect given the injuries, and anticipatory guidance and navigation towards services and resources. Early identification, assessment, and intervention are crucial with this population of caregivers and should be incorporated during the veteran's transition from active duty.

Children are highly impacted and many times not a focal point for social work practitioners working with the veteran, particularly in the VHA. Specific attention should be paid to the impact on children with attempts to assist spouses with role strain, but also attempts to normalize the child's lives by advocating for socialization and teaching families to protect children from witnessing the veteran's dysfunctional behaviors as this can influence future behaviors evidenced in the literature (Flake et al., 2009; Hayes et al., 2010; Pemberton et al., 2013). Subsidized childcare would be a solution for some caregivers who have to work, but are unable to leave their children with the veteran. Family counseling should also be more readily available to be inclusive of the children to work on reintegration and solutions focused at empowering the family system. Social workers should also assess role strain with parental caregivers who care for the veteran and the veteran's children. This was noted to be a source of stress for some parental caregivers and should not be overlooked. Education and resources for self-care should also be provided and should focus on self-care strategies that are efficient and easy to implement.

Lastly, it is essential that social workers take the time to speak with caregivers about intimacy. Often times, this is a subject that is not approached by practitioners, but

problems with intimacy can be an indicator of other underlying concerns and the veteran may not feel comfortable discussing this topic with their medical providers. Social workers can take the opportunity to be proactive and approach the topic of intimacy directly with the caregivers by assessing needs and exploring treatment options or interventions that aim to increase the emotional connectedness between the couple.

Implications for Future Social Work Practice and Research

There are many opportunities for social workers in the community and at VHA/military settings to improve upon current services based on this study. Social workers can advocate for more programming at their respective agencies that is more inclusive of the family system, including children. They can also develop specific courses and community supports targeted to this group of children and their families to assist the families with reintegration. Social workers could also advocate for a special form of subsidized daycare to be made available to newly reintegrating injured soldiers, giving caregivers a chance to assist the veteran upon return, but also allowing them to have reduced role strain. Social workers can attempt to develop a form of respite that is appropriate for the veteran. These veterans tend to be younger so utilizing traditional forms of respite such as adult day care and sitters may not be appropriate. Encouraging use of respite programs from Wounded Warrior Project and creating opportunities for veterans such as veteran centered activities, volunteer positions, or projects would serve two purposes; providing the caregiver with some time to focus on themselves, but also giving the veteran an opportunity to develop skills such as socialization and reintegration. Clinicians can also try to have classes or support groups for caregivers that coincide with skill building or treatment for veterans. They could also develop telehealth classes, on

demand classes, or online support groups that are available to caregivers at their convenience. Utilizing technology to deliver programming to this population of caregivers would also be beneficial to families and staff as it can result in cost savings to agencies and families, while reducing the burden placed on caregivers by allowing them to engaging in supportive services when opportunity allows.

Another area of need centers on financial planning and basic budgeting skills for caregivers and veterans. Many times, veterans and caregivers who are returning from active duty experience financial strains associated with transferring from active duty. Social workers can develop programs that teach and/or provide resources to these caregivers to assist with accumulated debt and money management which might prove to help reduce some of the financial stressors families are experiencing.

In terms of research, further studies should be completed to explore the impact of invisible injuries on children and should include studies with the children from the population as well as their families. This study supports the belief that children not only add additional strain to caregivers, but also face consequences themselves from what they are witnessing and experiencing. A larger comparative study should be completed with this population of caregivers with a comparison between caregivers who are in the CSP and those that are not. This would help determine how effective the CSP is and its impact. A larger version of this study would also be beneficial as this study was limited to caregivers in the NFSG area and is not representative of all caregivers in the CSP. Further research on military/veteran caregivers is warranted based on the limited findings in this study. The findings from this study suggest that caregivers who are veterans may be better able to adjust to caregiving than civilian caregivers, but more exploration is

needed with a larger representative sample. Lastly, research on service dog utilization and benefits for families should also be explored. The pets and service dogs seem to be an important part of the family system with numerous benefits to the veteran and the caregivers, and quite possibly the children in the home.

Limitations and Strengths

This study is limited given its non-representative sample and is not generalizable to the whole population of military caregivers for several reasons. Primarily, this group of caregivers is receiving financial support in the form of the financial stipend and also support from the CSP as needed, thereby placing them at an advantage with more resources compared to those who do not receive the assistance. In addition, this is a small portion of caregivers caring for veterans with invisible injuries from North Florida and South Georgia. The sample was also limited in terms of including a small number of male caregivers, parent caregivers, and veteran caregivers. More research is needed with males, parents, veteran caregivers, and same sex partners with larger sample sizes. A larger study that incorporates sampling from all geographical areas and those that have the stipend and those that do not would increase the generalizability and validity of the study.

For the quantitative portion of the study, there are concerns regarding secondary data usage, mainly collection error and administration of the ZBI, as the researcher did not administer the screening. For a more in-depth perspective, a study utilizing the full or the short Zarit burden scale could possibly yield a more encompassing view of caregiver burden in this population (Bachner & O'Rourke, 2007; Zarit et al., 1980). Causality

cannot be established because correlations were used to assess associations between variables and cross-sectional data were used.

Some responses by the caregivers in the qualitative study might have been biased as the researcher was also the coordinator for the CSP. It is possible that caregivers responded in a manner to questions about the actual CSP program to serve their own gain, i.e. requesting more money, indicating the need for money, financial resources, etc. as they may have believed that by expressing this, the researcher would be able to influence program decisions despite being informed that their answers would be kept confidential and would not affect their program status.

There was also concern about the honesty of responses given that most interviews took place in the veteran's home and the caregivers may not have been as forthcoming with sensitive issues so as to not offend the veteran. While every effort was made to ensure the privacy of the interview, as indicated in the data, veterans can be secretive and since these are sensitive topics, the validity or minimization of the responses must be recognized.

In terms of the qualitative results, a co-coder for all the interviews would have yielded more validity for the themes created in this study. The qualitative portion only had one interview that was co-coded in order to define and add codes to an already created set of codes based on interview questions and theory. Ideally every interview should have been co-coded and a consensus of 80% would have been acceptable for validity and inter-rater reliability based on a review of multiple inter-rater reliability suggestions (Neuendorf, 2002).

Despite study limitations, there were also strengths. This was one of the first studies that examined ZBI scores and other variables with post 9/11 veteran caregivers. This study was also triangulated with a mixed methods approach providing validation of results in each of the qualitative and quantitative portions of the study. Given the researcher was already familiar with and had relationships with the caregivers interviewed, there was already an established rapport which resulted in rich data being collected in the qualitative study. A large number of participants were available for the quantitative portion of the study yielding more robust results. Lastly, all of the participants volunteered to be a part of the qualitative study. There was no incentive to participate and many cited that they wanted to provide insight and assist in services and programs for other caregivers.

Conclusion

The goal of this dissertation study was to explore the essence of caregiving experiences among post 9/11 veteran caregivers caring for veterans with invisible injuries, specifically PTSD and TBI. The quantitative analyses revealed two significant findings. First, caregivers who had children in the home had a significantly higher level of caregiver stress than those who did not. This was the first study to report this finding. The second finding was that spousal caregivers had a higher level of caregiver stress compared to parent caregivers. This finding is congruent with previous studies of which caregiver stress was compared between parents and spouses in other populations of caregivers (Brodaty & Hadzi-Pavlovic, 1990; Gordon & Perrone, 2004; Pinquart & Sorenson, 2011; Verhaeghe et al., 2005).

The qualitative portion of the study also adds new findings to the literature by providing an in depth shared experience of post 9/11 veteran caregivers. Together, these findings demonstrate the complexities that veteran caregivers face daily. Social workers should familiarize themselves with these caregivers' distinct needs and challenges and provide support, empathy, and culturally competent care to this vulnerable population.

Overall, there are important ramifications for social workers in the field and for social work researchers. One implication is regarding the lack of preparation or transition from the active duty side post injury to the civilian world for the caregivers and their families. It seems that the family's adjustment may have been easier and the subjective demands may have been more manageable with some form of anticipatory guidance about the injuries and the impact they may potentially have on the families as well as comprehensive services to assist them in their caregiving journey. This might reduce impact to caregivers and their families significantly. While the CSP does provide some support and the VHA has made some substantial efforts to support these families, there are still numerous unmet needs that social workers can meet both at the VHA, but more so in the community settings (Patel, 2015).

Community social workers should not only familiarize themselves with this group's challenges, but also learn about the resources available to them as not all veterans frequent the VHA for healthcare (Patel, 2015). Further research is also warranted to obtain a more comprehensive picture of what those needs are by exploring veteran caregivers all across the nation including those that are not enrolled in the CSP and those who are not receiving care at the VHA. Lastly, it should be mentioned that social work values dictate that we provide advocacy for this at risk population. It is critical that

within their own agencies, practices and programs, social workers advocate for more resources and interventions for this population to help these caregivers and their families make an effective transition into their new roles. It is important to remember that these caregivers are serving and caring for those who have served and have sacrificed so much.

REFERENCES

- Alston, M. & Bowles, W. (2003). *Research for social workers: An introduction to methods* (2nd ed). New York, NY: Routledge.
- American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders*, (5th ed.). Washington, DC: Author
- Anderson, M. I., Simpson, G. K., Morey, P. J., Mok, M. M., Gosling, T. J., & Gillett, L. E. (2009). Differential pathways of psychological distress in spouses vs. parents of people with severe traumatic brain injury (TBI): multi-group analysis. *Brain Injury*, 23, 931-943. doi: 10.3109/02699050903302336
- Bachner, Y.G. & O'Rourke, N. (2007). Reliability and generalization of responses by care providers to the Zarit burden inventory. *Aging and Mental Health*, 11, 678-685.
- Baker, B. L., McIntyre, L. L., Blacher, J. J., Crnic, K. K., Edelbrock, C. C., & Low, C. C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230. doi:10.1046/j.1365-2788.2003.00484.x
- Barker, R. L. (2003). *The social work dictionary*. (5ed). Washington D.C.: NASW Press.
- Beckham, J.C., Lytle, B.L., & Feldman, M.E. (1996). Caregiver burden in partners of Vietnam war veterans with posttraumatic stress disorder. *Journal of Consulting and Clinical Psychology*, 64, 1068-1072.
- Bedard, M., Molloy, W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist*, 41, 652-657.
- Bolas, H., Wersch, A., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology & Health*, 22, 829-850. doi:10.1080/14768320601020154
- Borg, C., & Hallberg, I.R. (2006). Life satisfaction among informal caregivers in comparison with non-caregivers. *Scandinavian Journal of Caring Science*, 20, 427-438.

- Brenner, L. A., Ignacio, R. V., & Blow, F. C. (2011). Suicide and traumatic brain injury among individuals seeking Veterans Health Administration services. *The Journal of Head Trauma Rehabilitation*, 26, 257-264.
- Brodaty, H. & Hadzi-Pavlovic, D. (1990). Psychosocial effects on carers of living with persons with dementia. *Australia and New Zealand Journal of Psychiatry*, 24, 351–361.
- Calhoun, P. S., Beckham, J. C., & Bosworth, H. B. (2002). Caregiver burden and psychological distress in partners of veterans with chronic posttraumatic stress disorder. *Journal of traumatic stress*, 15(3), 205-212.
- Carretero, S., Garces, J., Rodenas, F., & Sanjose, V. (2009). The informal caregiver's burden of dependent people: theory and empirical review. *Archives Gerontology and Geriatrics*, 49, 74-79.
- Classen, S., Levy, C., Meyer, D.L., Bewernitz, M., Lanford, D.N., & Mann, W.C. (2011). Simulated driving performance of combat veterans with mild traumatic brain injury and posttraumatic stress disorder: A pilot study. *The American Journal of Occupational Therapy*, 65, 419-427.
- Clay, O. J., Grant, J. S., Wadley, V. G., Perkins, M. M., Haley, W. E., & Roth, D. L. (2013). Correlates of health-related quality of life in African American and Caucasian stroke caregivers. *Rehabilitation Psychology*, 58, 28-35. doi: 10.1037/a0031726
- Cohen, S. & Wills, T.A. (1985). Stress social support and the buffering hypothesis. *Psychological Bulletin*, 98, 310-357.
- Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Creswell, J.W. (2009). *Research Design* (3rd ed.). Thousand Oaks, CA: Sage.
- Creswell, J.W., & Plano Clark, V. L. (2007). *Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.
- DeGraff, A.H. (2002). *Caregivers and personal assistants*. Fort Collins, CO: Saratoga Access Publications, Inc.
- Department of Defense (DOD) (2011). Strengthening our military families. Retrieved July 13th 2013 from:
https://www.dol.gov/dol/milfamilies/strengthening_our_military_families.pdf

- Department of Defense (2013). DoD numbers for traumatic brain injury. Retrieved July 13, 2013 from: <http://www.dvbic.org/sites/default/files/u9/dod-tbi-worldwide-2000-2013Q1-as-of-130509.pdf>
- Department of Defense (2014). Casualty Report. Retrieved February 26, 2014 from: <http://www.defense.gov/casualty.pdf>
- Dow, B. and McDonald, J. (2003). Social support or structural change? Social work theory and research on care-giving. *Australian Social Work*, 56: 197–208. doi:10.1046/j.0312-407x.2003.00083.x
- Dupke, N.J., Plant, K.L., & Kosteas, J. (2016). Supporting Caregivers of Veterans Online: A Partnership of the National Council on Aging and VA. *Federal Practitioner*, 33, 41-46.
- Evans, L., Cowlshaw, S., Forbes, D., Parslow, R., & Lewis, V. (2010). Longitudinal analyses of family functioning in Veterans and their partners across treatment. *Journal Consulting and Clinical Psychology*, 78, 611-622. doi: 10.1037/a0020457
- Evans, S. W., Sibley, M., & Serpell, Z. N. (2009). Changes in caregiver strain over time in young adolescents with ADHD: The role of oppositional and delinquent behavior. *Journal of Attention Disorders*, 12, 516–524. doi:10.1177/1087054708322987.
- Evans, S. W., Sibley, M., & Serpell, Z. N. (2009). Changes in caregiver strain over time in young adolescents with ADHD: The role of oppositional and delinquent behavior. *Journal of Attention Disorders*, 12, 516–524. doi:10.1177/1087054708322987.
- Evans, S. W., Sibley, M., & Serpell, Z. N. (2009). Changes in caregiver strain over time in young adolescents with ADHD: The role of oppositional and delinquent behavior. *Journal of Attention Disorders*, 12, 516–524. doi:10.1177/1087054708322987.
- Fairweather, A., & Garcia, M. (2007). *Defining a new age of Veteran care: Primer for understanding Iraq and Afghanistan Veterans*. Retrieved February 7, 2013 from: <https://www.socialworkweb.com/nasw/index.cfm>
- Fine, M. D. (2011). Employment and informal care: Sustaining paid work and caregiving in community and home based care. *Ageing International*, 37, 57-68.
- Fischer, E. P., Sherman, M. D., Han, X., & Owen, R. R. (2013). Outcomes of participation in the REACH multifamily group program for Veterans with PTSD

and their families. *Professional Psychology: Research and Practice*, 44, 127-134. doi: 10.1037/a0032024

- Flake, E.M., Davis, B.E., Johnson, P.L., & Middleton, L.S. (2009). The psychological effects of deployment on military children. *Journal of Developmental Behavioral Pediatrics*, 30, 271-278.
- Fox, S., & Brenner, J. (2012). Family caregivers online. *Washington, DC: Pew Internet & American Life Project*.
- Gordon, P.A., & Perrone, K.M. (2004). When spouses become caregivers: Counseling implications for younger couples. *Journal of Rehabilitation*, 70, 27-32.
- Griffin, J. M., Friedemann-Sánchez, G., Hall, C., Phelan, S., & van Ryn, M. (2009). Families of patients with polytrauma: Understanding the evidence and charting a new research agenda. *The Journal of Rehabilitation Research and Development*, 46, 879. doi: 10.1682/jrrd.2008.08.0104
- Griffin, J. M., Friedemann-Sánchez, G., Jensen, A. C., Taylor, B. C., Gravely, A., Clothier, B., & Ceperich, S. (2012). The invisible side of war: Families caring for US service members with traumatic brain injuries and polytrauma. *The Journal of head trauma rehabilitation*, 27, 3-13.
- Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, 2, 323–330.
- Harben, J. (2006). Mental health advisory team III findings released. Retrieved March 17, 2014, from: <http://armymedicine.mil/Pages/reports.aspx>
- Hayes, J., Wakefield, B., Andersen, E.M., Scherrer, J., Traylor, L., Wiegmann, P., Denmark, T., & DeSouza, C. (2010). Identification of domains and measures for assessment battery to examine well being of spouses of OIF/OEF Veterans with PTSD. *Journal of Rehabilitation Research and Development*, 47, 825-840. doi: 10.1682/JRRD.2009.04.0049.
- Hutchison, E.D. (2011). *Dimension of human behaviors: The changing life course* (4th ed.). Thousand Oaks, CA: Sage
- Hycner, R. (1985). Some guidelines for the phenomenological analysis of interview data. *Human Studies*, 8, 279-303.

- Jakupcak, M., Vannoy, S., Imel, Z., Cook, J. W., Fontana, A., Rosenheck, R., & McFall, M. (2010). Does PTSD moderate the relationship between social support and suicide risk in Iraq and Afghanistan war Veterans seeking mental health treatment? *Depression and Anxiety*, 27, 1001-1005.
- Jakupcak, M., & Varra, E. M. (2011). Treating Iraq and Afghanistan War Veterans with PTSD who are at high risk for suicide. *Cognitive and Behavioral Practice*, 18, 85-97. doi: 10.1016/j.cbpra.2009.08.007
- Jordan, B. K., Marmar, C. R., Fairbank, J. A., Schlenger, W.E., Kulka, R.A., Hough, R.L., & Weiss, D.S. (1992). Problems in families of male Vietnam Veterans with posttraumatic stress disorder. *Journal of Consulting and Clinical Psychology*, 60, 916-926.
- Kang, H.K., Bullmna, T.A., Smolenski D.J., Skopp N.A., Gahm G.A., & Reger, M.A. (2015). Suicide risk among 1.3 million veterans who were active duty during the Iraq and Afghanistan wars. *Annals of Epidemiology*, 25, 96-100. doi: 10.1016/j.annepidem.2014.11.020.epub
- Kaniasty, K., & Norris, F. H. (2008). Longitudinal linkages between perceived social support and posttraumatic stress symptoms: sequential roles of social causation and social selection. *Journal of Traumatic Stress*, 21, 274-281. doi: 10.1002/jts.20334
- Kennedy, J., Jaffee, M. S., Leskin, G. A., Stokes, J. W., Leal, F. O., & Fitzpatrick, P. J. (2007). Posttraumatic stress disorder and posttraumatic stress disorder-like symptoms and mild traumatic brain injury. *Journal of Rehabilitation Research and Development*, 44, 895-920.
- Krammer, B. J, & Thompson, E. H. (2005). *Men as caregivers*. New York, NY: Prometheus Books.
- Lambert, J.E., Engh, R., Hasbun, A., & Holzer, J. (2012). Impact of posttraumatic stress disorder on the relationship quality and psychological distress of intimate partners: A meta-analytic Review. *Journal of Family Psychology* 26, 729-737. doi: 10.1037/a0029341
- Laverty, S.M. (2003). Hermeneutic phenomenology and phenomenology: a comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2. Article 3. Retrieved September 5, 2010 from http://www.ualberta.ca/~iiqm/backissues/2_3final/pdf/laverty.pdf
- Lawton, M.P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*. 9, 179-186.

- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.
- Lazarus, R.S. & Folkman, S. (1984). *Stress, Appraisal and Coping*. New York, NY: Springer Publishing Company.
- Lee, J. A., Walker, M., & Shoup, R. (2001). Balancing elder care responsibilities and work: The impact on emotional health. *Journal of Business and Psychology*, 16, 277-289.
- Lew, H.L., Kraft, M., Pogoda, T.K., Amick, M.M., Woods, P., & Cifu, D.X. (2011). Prevalence and characteristics of driving difficulties in Operation Iraqi Freedom/Operation Enduring Freedom combat returnees. *Journal of Rehabilitation Research & Development*, 48, 913-926. doi: 10.1682/JRRD.2010.08.0140
- Levin, A. (2008). Blast injury sequelae linked to PTSD. *Psychiatric News*, 43, 23.
- Link, P. E. & Palinkas, L. A. (2013). Long-term trajectories and service needs for military families. *Clinical Child Family Psychological Review*, 16, 376-393.
- Livingston, L.A., Kennedy, R.E., Marwitz, J.H., Arango-Lasprilla, J.C., Rapport, L.J., Bushnik, T., & Gary, K.W. (2011). Predictors of family caregiver's life satisfaction after traumatic brain injury at one and two years post injury: A longitudinal multi-center investigation. *Neurorehabilitation*, 27, 73-81.
- Lorig, K., Thompson-Gallagher, D., Traylor, L., Ritter, P. L., Laurent, D. D., Plant, K., Hahn, T. J. (2012). Building Better Caregivers: A Pilot Online Support Workshop for Family Caregivers of Cognitively Impaired Adults. *Journal of Applied Gerontology*, 31, 423-437. doi: 10.1177/0733464810389806
- Lutzky, S.M. & Knight B.G. (1994). Explaining gender differences in caregiver distress: The roles of emotional attentiveness and coping styles. *Psychology and Aging*, 9, 513-519.
- Macera, C. A., Aralis, H. J., MacGregor, A. J., Rauh, M. J., & Galarneau, M. R. (2012). *Postdeployment symptom changes and traumatic brain injury and/or posttraumatic stress disorder in men* (No. NHRC-11-22). Navel Health Research Center San Diego, CA
- Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation*. California: John Wiley & Sons Inc.

- Mertler, C.A. & Vannata, R.A. (2010). *Advanced and multivariate statistical analysis*. Glendale, CA: Pyczak Publishing.
- Miller, T.W., Houston, L., & Goodman, R.W. (1994). Clinical issues in psychosocial rehabilitation for spouses with physical disabilities. *Journal of Development and Physical Disabilities*, 6, 43-53.
- Milinki, A. K. (Ed.). (1999). *Cases in qualitative research: Research reports for discussion and evaluation*. Pyczak Pub.
- Milliken, C. S., Auchterlonie, J. L., & Hoge, C. W. (2007). Longitudinal assessment of mental health problems among active and reserve component soldiers returning from the Iraq war. *JAMA*, 298, 2141–2148.
- Monahan, D. J., & Hooker, K. (1997). Caregiving and social support in two illness groups. *Social work*, 42, 278-287.
- Monson, C.M. & Taft, C.E. (2005). PTSD and intimate partner relationships. *PTSD Research Quarterly*, 16.
- Montgomery, R.J.V., Gonyea, J.G., & Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations*, 34, 19-26.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Nabors, N., Seacat, J., & Rosenthal, M. (2002). Predictors of caregiver burden following traumatic brain injury. *Brain Injury*, 16, 1039-1050. doi: 10.1080/02699050210155285
- National Alliance for Caregiving (NAC), (2010). Caregivers of Veterans: Serving on the homefront. Retrieved March 30th, 2013 from: http://www.caregiving.org/data/2010_Caregivers_of_Veterans_FULLREPORT_WEB_FINAL.pdf
- Navaie-Waliser, M., Spriggs, A., & Feldman, P.H. (2002). Informal caregiving: Differential experiences by gender. *Medical Care*, 40, 1249–1259.
- Neuendorf, K.A., 2002. *The content analysis guidebook*. Thousand Oaks, CA: Sage.
- NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 8, 2008
- O'Donnell, L., Begg, L, Lipson, L, & Elvander, E. (2011). Trauma spectrum disorders: Emerging perspectives on the impact of military and Veteran families. *Journal of Loss and Trauma*, 16, 284-290. doi:10-1080/15325024.2010.519269.

- Office of the Surgeon Multi-National Force-Iraq and Office of the Surgeon General United State Army Medical Command. *Mental Health Advisory Team V Operation Iraqi Freedom 06-08*. Retrieved March 17, 2014 from: <http://armymedicine.mil/Documents/Redacted1-MHATV-OIF-4-FEB-2008Report.pdf>.
- Padgett, D. K. (1998). *Qualitative methods in social work*. Thousand Oaks, CA: Sage.
- Patel, B. R. (2015). Caregivers of veterans with “invisible” injuries: What we know and the implications for Social Work Practice. *Social Work*, 60, 9-17. doi: 10.1093/sw/swu043
- Payne, M., (2005). *Modern Social Work Theory* (3rd ed.). Chicago, IL: Lyceum Books Inc.
- Pearlin, L. I. (2010). The life course and the stress process: Some conceptual comparisons. *Journal of Gerontology*, 65B, 207-215.
- Pearlin, L. I., Mullan, J.T., Semple, S.J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Pemberton, J. R., Kramer, T. L., Borrego, J., Jr., & Owen, R. R. (2013). Kids at the VA? A call for evidence-based parenting interventions for returning Veterans. *Psychological Services*, 10, 194-202. doi: 10.1037/a0029995
- Phelan, S.M., Griffin, J.M., Hellerstedt, W.L., Sayer, N.A., Jensen, A.C., Burgess, D.J., & Ryan, M.V. (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.
- Pinquart, M., & Sorensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: a meta-analytic comparison. *Psychology and Aging*, 26, 1-14. doi: 10.1037/a0021863
- Pringle, J., Hendry, C., & McLafferty, E. (2011). Phenomenological approaches: challenges and choices. *Nurse Researcher*, 18, 7-18. doi: 10.7748/nr2011.01.18.2.7.c8280
- Rabin, C. & Nardi, C. (1991). Treating posttraumatic stress disorder couples: A psycho-education program. *Community Mental Health Journal*, 27, 209-224.

- Ramchand, R., Tanielian, T., Fisher, M. P., Vaughan, C.A., Trail, T. E., Batka, C., Voorhies, P., Robbins, M., Robinson, E., & Ghosh-Dastidar, B. (2014). *Hidden heroes: America's military caregivers*. Retrieved April 24, 2016 from: http://www.rand.org/pubs/research_reports/RR499.html.
- Ragsdale, K. A., Neer, S. M., Beidel, D. C., Frueh, B. C., & Stout, J. W. (2013). Posttraumatic stress disorder in OEF/OIF veterans with and without traumatic brain injury. *Journal of Anxiety Disorders*, 27, 420-426. doi: 10.1016/j.janxdis.2013.04.003
- Ray, S. L., & Vanstone, M. (2009). The impact of PTSD on Veterans' family relationships: an interpretative phenomenological inquiry. *International Journal of Nursing Studies*, 46, 838–847.
- Sander, A. M., Davis, L., Struchen, M. A., Atchison, T., Sherer, M., Malec, J. F., & Nakase-Richardson, R. (2007). Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *Neurorehabilitation*, 22, 9-17.
- Savundranayagam, M.Y., & Montgomery, R.J.V. (2010). Impact of role discrepancies on caregiver burden among spouses. *Research on Aging*, 32, 175-199.
- Sayers, S. L., Farrow, V. A., Ross, J., & Oslin, D. W. (2009). Family problems among recently returned military veterans referred for a mental health evaluation. *Journal of Clinical Psychiatry*, 70, 163-170.
- Sayer, M.A., Noorbaloochi, S., Frazier, P., Carlson, K., Gravley, A., & Murdoch, M. (2010). Reintegration problems and treatment interested among Iraq and Afghanistan combat Veterans receiving VA medical care. *Psychiatric Services*, 61, 589-597.
- Summerall, E. L. (2008). *Traumatic brain injury and PTSD fact sheet*. Retrieved January 19, 2013 from: <http://www.ptsd.va.gov/professional/co-occurring/traumatic-brain-injury-ptsd.asp>
- Taft, C. T., Watkins, L. E., Stafford, J., Street, A. E., & Monson, C. M. (2011). Posttraumatic stress disorder and intimate relationship problems: A meta-analysis. *Journal of Consulting and Clinical Psychology*, 79, 22–33.
- Tanielian, T., & Jaycox, L.H. (2008). *Invisible wounds of war: Psychological and cognitive injuries their consequences and services to assist recovery*. Retrieved March 18, 2013 from: http://www.rand.org/content/dam/rand/pubs/monographs/2008/RAND_MG720.pdf

- Tanielian, T., Ramchand, R., Fisher, M. P., Sims, C. S., Harris, R.S., & Harrell, M.C. (2013). *Military caregivers: Cornerstones of support for our nations wounded, ill, and injured veterans*. Retrieved March 18, 2013 from: http://www.rand.org/pubs/research_reports/RR244
- The Caregivers and Veterans Omnibus Health Services Act, Public Law: 111-163 (2010) (enacted).
- Thoresen, S., Mehlum, L., Rosamb, E., & Tonnessen, A. (2006). Risk Factors for completed suicide in Veterans of peacekeeping; repatriation, negative life events, and marital status. *Archives of Suicide Research*, 10:353-63.
- United States Department of Veterans Affairs (2016). *Monday Morning Workload Report*. Retrieved July 16, 2016 from: http://benefits.va.gov/reports/detailed_claims_data.asp
- United States Department of Veterans Affairs (2007). *Polytrauma system of care*. Retrieved January 16, 2013 from:
- United States Department of Veterans Affairs (2007). *National Center for PTSD*. Retrieved February 12, 2013 from: <http://www.ptsd.va.gov/public/PTSD-overview/basics/index.asp>
- United States Department of Veterans Affairs, (2010). *National Caregiver Training Program: Caregiver Workbook*. Easter Seals. Washington D.C: Easter Seals.
- United States Department of Veterans Affairs, (2012). *VA Mobile Health Program*. Retrieved March 17, 2014 from: <https://mobilehealth.va.gov/pilots>
- United States of America (2011). *Strengthening our Military Families*. Retrieved July, 2016 from: https://www.dol.gov/dol/milfamilies/strengthening_our_military_families.pdf
- VA Caregiver Support. (n.d.). Retrieved July 16, 2016, from: http://www.caregiver.va.gov/support/support_services.asp
- 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. doi:10.1111/j.1365-2702.2005.01126.x
- Wheaton, B. (1985). Models for the stress buffering functions of coping resources. *Journal of Health and Social Behavior*, 26 352-364.

- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method account*. Buckingham, PA: University Press.
- Young, H., & Grundy, E. (2008). Longitudinal perspectives on caregiving, employment history and marital status in midlife in England and Wales. *Health and Social Care in the Community*, *16*, 388-399. doi: 10.1111/j.1365-2524.2007.00750.x
- Yount, R. A., Olmert, M. D., & Lee, M. R., (2012). Service dog training program for treatment of Post-Traumatic Stress Disorder in service members. *The US Army Medical Department Journal*. 63-69.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly. Correlates of feelings of burden. *Gerontologist*, *20*, 649-655.
- Zarit, S. H., & Zarit, J.M. (2007). *Mental Disorders in Older Adults: Fundamentals of Assessment and Treatment*. New York, NY: Springer Publications.

APPENDIX A: CSP ELIGIBILITY CRITERIA



ELIGIBILITY CRITERIA FOR FAMILY CAREGIVER PROGRAM



In order to be eligible a person must meet **all primary criteria (1 through 7)**:

Primary Criteria 1 - Veteran (or Servicemember undergoing medical discharge) incurred or aggravated a serious injury in the line of duty on or after September 11, 2001.

A "serious injury" is any injury, including traumatic brain injury, psychological trauma, or other mental disorder.

(and) Primary Criteria 2 - This serious injury renders the Veteran or servicemember in need of a Family Caregiver to:

1. Support the Veteran or servicemember's health and well-being;
2. Perform personal functions required in everyday living; **and**
3. Ensure the Veteran or servicemember remains safe from hazards or dangers incident to his or her daily environment.

(and) Primary Criteria 3 - The Veteran or servicemember requires at a **minimum six months** of continuous and approved caregiver support, based on **either A, B, C, or D below**:

A. Inability to Perform One or More of the Following Activities of Daily Living:

1. Dressing and Undressing: Dress or undress him or herself;
2. Personal Hygiene: Bathe in order to keep self clean;
3. Grooming: Groom in order to keep self presentable;
4. Toileting: Toilet or attend to toileting without assistance;
5. Feeding oneself: Feed self through loss of coordination of upper extremities or through extreme weakness or inability to swallow or requires other non-oral means of nutrition;
6. Mobility: Transfer unassisted (i.e. bed to chair, to toilet, to shower);
7. Frequent need of adjustment of any special prosthetic or orthopedic appliance which by reason of the particular disability cannot be done without aid (this will not include the adjustment of appliances that non-disabled persons would be unable to adjust without aid, such as supports, belts, lacing at the back, etc.)



ELIGIBILITY CRITERIA FOR FAMILY CAREGIVER PROGRAM



(Continued)

(or) B. Need for Supervision, Protection, or Assistance based on symptoms or residuals of neurological or other impairment or injury (including Traumatic Brain Injury, psychological trauma or other mental disorders) due to any ONE of the following:

1. Seizures (blackouts or lapses in mental awareness, etc.);
2. Difficulty with planning and organizing (such as the ability to adhere to medication regimen);
3. Safety risks (wandering outside the home, danger of falling, using electrical appliances, etc.);
4. Difficulty with sleep regulation;
5. Delusions or hallucinations;
6. Difficulty with recent memory;
7. Self regulation (being able to moderate moods, agitation or aggression, etc.).

(or) C . Veteran or servicemember has a psychological trauma or a mental disorder that has been scored by a licensed mental health professional, with a Global Assessment of Functioning (GAF) score of 30 or less, continuously during the 90-day period immediately preceding the date on which VA initially received the caregiver application.

VA will consider a GAF score to be "continuous" if there are at least two scores during the 90-day period (one that shows a GAF score of 30 or less at the beginning of the 90-day period and one that shows a GAF score of 30 or less at the end of the 90-day period) and there are no intervening GAF scores of more than 30.

(or) D. Veteran has been rated 100 percent service connected disabled with special monthly compensation that includes aid and attendance allowance.

(and) Primary Criteria 4 - The Family Caregiver Program is in the best interest of the Veteran or servicemember because it is:

- A. Likely to **significantly enhance** the Veteran or servicemember's ability to live safely in a home setting;
- B. Supports the Veteran or servicemember's potential progress in rehabilitation, if such potential exists; **and**
- C. Creates an environment that supports the health and well-being of the Veteran or servicemember.



ELIGIBILITY CRITERIA FOR FAMILY CAREGIVER PROGRAM



(Continued)

(and) Primary Criteria 5 - The Veteran or servicemember will receive care at home once caregiver training is complete.

(and) Primary Criteria 6 - The Veteran or servicemember will receive ongoing care from a Patient Aligned Care Team (PACT) or other VA health care team as a requirement for participation in the program

(and) Primary Criteria 7 - Personal care services provided to the Veteran or servicemember by the Family Caregiver will not be simultaneously and regularly provided by or through another individual, entity, or program .

APPENDIX B: DEFINITIONS

Definitions Table:

Activities of Daily Living: “Routine, day to day *activities of daily living*...Assistance with some or all of the following: Urinary collection device or self-catheterization supplies, bowel program, bathing or showering, getting dressed or undressed, transfers among beds, wheelchairs, commode chair, car, food preparation and eating, taking medication, and wound care” (DeGraff, p. 24).

Caregiver: The social work dictionary (2003) defines a caregiver as a person who provides care in the form of physical, social and emotional needs for an individual that is typically unable to meet their own needs and is dependent on another for care.

Informal: The informal caregiver is any caregiver that is not paid and provides the provision of care that surpasses the traditional social relationship that normally exists between those individuals (Kramer & Thompson, 2005).

Caregiver Burden: The adverse effects, consequences, and stress associated with the providing care for another which can include physical, psychological and financial repercussions (Montgomery, Gonyea, & Hooyman, 2001; Zarit, Reever, & Bach-Peterson, 1980).

Subjective burden. The caregiver’s insight into how the disability impacts their lives, their identity and their relationship

Objective burden. Objective burden can be categorized as the level of disability, the extent of cognitive and behavioral problems of the care recipient, (Zarit & Zarit, 2007)

Caregiver Coping: Efforts to adapt both behaviorally and cognitively to internal and/or external demands of caregiving that have exceeded an individual's capabilities and/or availability of resources (Lazarus & Folkman, 1984).

Instrumental Activities of Daily Living (IADL): Includes: phone use, going grocery shopping, making meals, completing housekeeping, laundry, use of transportation, ability to take medications, and managing finances (Lawton & Brodaty, 1969).

Operation Enduring Freedom: (OEF): War that was launched by the United States on October 7, 2001 in response to US domestic terrorism. The goals of this conflict was to remove Taliban regime centered in Afghanistan and other Al-Qaeda operatives including Osama bin Laden responsible for terror attacks worldwide. This conflict is ongoing to present date.

Operation Iraqi Freedom: (OIF): War that was launched by the United States and Britain on March 20, 2003 in Iraq in a response to a threat of weapons of mass destruction that were present in Iraq. This conflict remains ongoing to present date.

Post Traumatic Stress Disorder: Eight Criterion are used to diagnose PTSD and include A) history of exposure to a traumatic event B) intrusion symptoms, C) avoidance symptoms, D) negative alterations in cognitions and mood, and E) alterations in arousal and reactivity. F) duration of symptoms of more than one month G) functional impairment; and, H) symptoms as not caused by medication, substances, or other

disorders. Two conditions include a delayed presentation and a dissociative subtype of PTSD (American Psychiatric Association, 2013).

Stipend: Financial compensation given to caregivers based on a Veterans needs assessment and for the sacrifices they make as caregivers for Veterans. Stipend amounts vary and have three Tiers.

The Caregivers and Veterans Omnibus Health Services Act of 2012 (Public Law: 111- 163): Public law allowing for Veteran caregivers to receive services and compensation based on eligibility requirements.

Traumatic Brain Injury: an injury caused by a significant blow to the head (USDVA Polytrauma Center, 2007).

Mild. confusion or disorientation for less than 24 hours; a loss of consciousness that is less than 30 minutes; memory loss that last up to 24 hours; and with brain imaging that shows no signs of impairment

Moderate. confusion or disorientation for more than 24 hours; a loss of consciousness that is more than 30 minutes, but less than 24 hours; memory loss between 24 hours and seven days; and with brain imaging that shows no signs or some signs of impairment

Severe. confusion or disorientation for more than 24 hours; a loss of consciousness for more than 24 hours; memory loss greater than 7 days; and with brain imaging that shows no signs or some signs of impairment

Penetrating. This is head injury that results from projectiles, bone fragments or knives that penetrate through the skull and into the dura mater or outer layer of the meninges.

Not Classifiable. These injuries do not fit into the above named categories.

There is no specific definition (DOD, 2013).

Veteran/Military Caregivers (VCG): A family member, friend or acquaintance that provides care in many forms to a veteran or current military member who is suffering from a disability or injury, either physical or mental, that happened during their time in the armed forces (Tanielian et al, 2013).

APPENDIX C: INTERVIEW GUIDE

NFSG CG qualitative Interview Guide

<p>Veteran Characteristics/ Demographics</p>	<ol style="list-style-type: none"> 1. Can you tell us about how your loved one got injured? How and where? (if MVA, ask if in blast if deployed) 2. What about for the person you care for. Is he married, divorced...<i>(Family composition at time of interview, including marital status; employment status/productive activities; changes in sociodemographics)</i> 3. What is the Veteran's service connection?
<p>Family Characteristics</p>	<ol style="list-style-type: none"> 4. Can you give us a picture of who the members of your family are, how old they are, and what they do for a living? (Family composition at time of interview, employment status; changes in sociodemographics)
<p>Caregiving Experiences and Caregiver Well-being, individual resources, life course.</p>	<ol style="list-style-type: none"> 5. In the initial stages of caregiving, you might have imagined the experience is going to be one way but in fact the caregiving experience is shaped by your loved one, by the providers, by your financial and social resources. What has been the most challenging time and why? (initially and currently) 6. What is to be a caregiver? <i>(probe: reciprocity, obligation, is caregiving a life-time commitment?)</i> if interviewee does not consider herself a CG, why not? 7. How did you end up being a caregiver? <i>(probe family negotiation)</i> 8. How did the injury change your life course/vision/goals? <i>(probe: time distribution, money, emotions, relationships, opportunities given up, changes in family/work balance challenges)</i> 9. How are you doing physically and emotionally? <i>(probe: What do you feel guilty about? (not having done more?))</i> 10. Do you have the ability to go on vacation, to continue your work, to lead the life you want to lead? <i>(probe ...Do you feel "the leash" syndrome, like you can't be away for long? Who else in your family feels this way?)</i> 11. What strategies have you developed to be able to be a caregiver. For example, have you taken up exercise, or going to church, get online, or do you write now in a journal or see a counselor? 12. Share with us the rewards you get from caregiving

<p>Caregiver burden or adaptation: Objective /Subjective demands and Financial Resources and burden</p>	<p>Families' views on caregiving demands; views on what constitutes a barrier and a facilitator to caregiving. Financial resources available to the family and veteran and used in order to perform caregiving activities; financial burden, sources/reasons of burden, and strategies to alleviate burden.</p> <p>13. Currently, what makes your job as a caregiver easier? <i>(probe: control over financial resources and decisions, pace, monotony, physical demands, psychological/cognitive/emotional demands, social support, community resources, resources, DoD, and VA services and benefits available to facilitate caregiving)</i> pets?life long case manager?contacted congress person? Filed for congressional inquiry?</p> <p>14. Currently, what makes your job as a caregiver more challenging? <i>(probe: control over resources and decisions, pace, (monotony, physical demands, psychological/cognitive/emotional demands, social support, community resources, financial challenges now and in future, into emotional labor, putting on an emotional façade in order to provide quality care, Navigating the medical system, the veteran system and Department of Defense benefits, and the health insurance come at a time when you are/were stressed)</i></p> <p>15. What was helpful and what could have been better? Families' descriptions about other life demands such as parenting and elder care and work for pay; views on what constitutes a barrier and a facilitator to fulfilling these; views on how caregiving affects other life-demands.</p> <p>16. Tell us about other responsibilities that you have, like your job, caring for your kids or an elderly person. What about caregiving makes it more difficult to fulfill these responsibilities?</p> <p>17. What makes it easier?</p> <p>18. What have been the effects of your caregiving on other family members? <i>(probe: small children having less attention, more daycare time, was it traumatic for siblings who were growing up? for example, traumatic and depressing to have a 24 year old sibling in a nursing home)</i></p>
<p>Social Support</p>	<p>Families' descriptions of the characteristics of their family structure and social network; Families' views on the role of their social resources in caregiving.</p> <p>19. We imagine that you have experienced social support from a variety of people, or groups. Can you share your experience <i>(probe about social undermining)</i></p>

Caregiver Support Program	<p>20. How has the caregiver support program impacted your family? Would could be better? What is working well?</p> <p>21. Has the stipend alleviated any stress, strain or worries you may have had before the stipend? Is so, how and if not why not?</p> <p>22. Has the stipend impacted your ability to balance work and caregiving?</p>
Social Media	<p>23. How has the internet played a role in caregiving? (<i>probe about blogs, social media, twitter, support groups, caregiver sites</i>)</p> <p>24. Some people feel that technology isolates people from others, others feel it brings them close to other. Can you explain if this has impacted you in the same way, why or why not?</p>
Family Wellbeing	<p>25. How would you say your family is doing as a whole since the injury?</p> <p>26. What characteristics do you feel your family has that have allowed you and your family to <u>adjust</u> to the crisis? (<i>probe: cooperation, commitment, communication, connectedness—family rituals/traditions, routines, family vacation/recreation</i>)</p> <p>27. How have your family dynamics changed/adapted since the injury to keep its cohesion/integrity? (<i>probe: cooperation, commitment, communication, connectedness—family rituals/traditions, routines, family vacation/recreation</i>)</p> <p>28. Can you share the experiences of other family members with your loved one’s injuries? Their role...how about siblings of XX having to be future caregivers.***For Parents CG’s.</p> <p>29. Can you share how your children were impacted by the Veterans return and how they have adapted to your family members injury?</p> <p>30. Tell me how having children in the home has impacted caregiving in positive ways and negative ways?</p> <p>31. Is the returning veteran in a caregiver role with the children?*** Questions for CG with Children</p>

***Some questions are from the FACES Qualitative Interview Guide, created at the

Minnesota VHA.

APPENDIX D: IRB DOCUMENTS

USF and UF Authorization Agreement

IRB Authorization Agreement

Name of Institution or Organization Providing IRB Review:

University of Florida Board of Trustees, a public body corporate (UF)
Institutional Review Board-01

IRB Registration #: 00000335 (IRB #1) Federal Wide Assurance (FWA) #: 00005790

Name of Institution Relying on the Designated IRB:

University of South Florida Board of Trustees, a public body corporate (USF)

Federal Wide Assurance (FWA) #: FWA 00000737

The Officials signing below agree that the UNIVERSITY OF SOUTH FLORIDA (USF) may rely on the UNIVERSITY OF FLORIDA IRB-01 (UF) for review and continuing oversight of research study described below.

USF, UF, and the NORTH FLORIDA/SOUTH GEORGIA VETERAN'S HEALTH SYSTEM (NF/SG VHS) agree to the following:

- This agreement pertains only to the following specific protocol:
 - *Caregivers of Veterans with Serious Invisible Injuries from Iraq*
 - *UF IRB#: 201400365*
 - *Principal Investigator: Beena Patel (affiliated with the NF/SG VHS and USF)*
- The review performed by UF IRB-01 will meet the human subject protection requirements of USF's OHRP (Office for Human Research Protections)-approved FWA.
- UF IRB-01 will follow written procedures for reporting its findings and actions to appropriate officials at USF.
 - Relevant minutes of IRB meetings will be made available to USF upon request. USF remains responsible for ensuring compliance with the IRB's determinations and with the terms of its OHRP-approved FWA.
- The PI named above will be responsible for forwarding copies of approval notices from the reviewing IRB to the USF IRB.
- This document must be kept on file by both parties and provided to OHRP upon request.
- USF agrees to designate UF IRB-01 on its OHRP-approved FWA.

University of Florida Board of Trustees

David P. Norton, PhD
Vice President for Research

Date

North Florida/South Georgia Veteran's Health System

Thomas Wisnieski, MPA, FACHE
Director

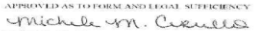
Date

University of South Florida Board of Trustees



Paul R. Sanberg, PhD, DSc
Senior Vice President for Research & Innovation

12-15-14
Date

APPROVED AS TO FORM AND LEGAL SUFFICIENCY

Michele Curcio, JD
Associate General Counsel - University of South Florida

UF IRB Approval Letter (2014-2015)



Health Center Institutional Review Board
FWA00005790

PO Box 100173
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DATE: 11/25/2014
TO: Bina Patel
Malcolm Randall VA Medical Center
Gainesville, Florida 32608
FROM: Peter Iafrate, Pharm.D
Chair IRB-01
IRB#: **IRB201400365**
TITLE: Caregivers of Veteran's with Serious "Invisible" Injuries from Iraq
and Afghanistan

Approved As Expedited
(Contingencies Met)

Expires on: 11/22/2015

On 11/25/2014, this project was determined to be approvable with contingencies. The required contingencies were submitted and subsequently approved on 11/25/2014. This study is approved as expedited as it poses minimal risk and is approved under the following expedited category/categories:

5. Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). [Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. (45 CFR 46.101[b][4].) This listing refers only to research that is not exempt.]
7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. [Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. (45 CFR 46.101(b)(2) and (b)(3).) This listing refers only to research that is not exempt.]

Approval Includes, but is not limited to:

Dated and watermarked IRB-approved Informed Consent Form

Consent Waiver Type:

Full Waiver of Informed Consent	Subjects will not be informed nor will consent be sought or obtained prior to their involvement in the research (including collection of data from identifiable records or tissue)
---------------------------------	--

HIPAA Waiver Type: to enroll subjects in the study

Special notes to Investigator: Research cannot begin until 1) USF Approval has been obtained 2) A Project Revision has been submitted and approved to UF IRB-01. A stamped Informed Consent Form will not be provided until the Project Revision has been submitted and approved. Within the Project Revision, please note that a stamped version of the ICF will be needed, attach copies of the final USF approval (Miscellaneous Attachments page), revise the Recruitment Letter to include the USF approval dates (Recruitment Methods page) and attach a final copy of the VA Privacy Officer Review (VA Research page).

Reviewer Notes: 0 Reviewer Notes

Principal Investigator Responsibilities:

The PI is responsible for the conduct of the study. Please review these responsibilities described at: <http://irb.ufl.edu/irb01/researcher-information/researcherresponsibilities.html>

Important responsibilities described at the above link include:

- Using currently approved consent form to enroll subjects (if applicable)
- Renewing your study before expiration
- Obtaining approval for revisions before implementation
- Reporting Adverse Events
- Retention of Research Records
- Obtaining approval to conduct research at the VA
- Notifying other parties about this project's approval status

cc:

The Foundation for The Gator Nation
An Equal Opportunity Institution

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information. Any other distribution, copying, or disclosure is strictly prohibited. If you are not the intended recipient, please notify the sender and destroy this message immediately. Unauthorized access to confidential information is subject to federal and state laws and could result in personal liability, fines, and imprisonment. Thank you.

UF IRB Approval Letter (2015-2016)



Health Center Institutional Review Board
FWA00005790

PO Box 100173
Gainesville FL 32610-0173
Telephone: (352) 273-9600
Facsimile: (352) 273-9614

DATE: 9/30/2015

TO: Bina Patel
Malcolm Randall VA Medical Center
Gainesville, Florida 32608

FROM: Peter Iafrate, Pharm.D
Chair IRB-01

IRB#: **2015 Review for IRB201400365**

TITLE: Caregivers of Veteran's with Serious "Invisible" Injuries from Iraq and Afghanistan

Approved as Expedited: Continuing Review **Expires on: 9/30/2016**

On 9/30/2015, the IRB re-approved you to continue conducting the above-listed research project. You are approved to enroll **200** subjects. This study is approved as expedited because it poses minimal risk and is approved under the following expedited category/categories:

5. Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis). [Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. (45 CFR 46.101[b][4].) This listing refers only to research that is not exempt.]
7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. [Note: Some research in this category may be exempt from the HHS regulations for

the protection of human subjects. (45 CFR 46.101(b)(2) and (b)(3).)
This listing refers only to research that is not exempt.]

Approval Includes:

Dated and watermarked IRB-approved Informed Consent Form
Recruitment Letter, Oral Script, and Recruitment Flyer

Consent Waiver Type:

Full Waiver of Informed Consent	Subjects will not be informed nor will consent be sought or obtained prior to their involvement in the research (including collection of data from identifiable records or tissue)
---------------------------------------	--

HIPAA Waiver Type: to enroll subjects in the study

Principal Investigator Responsibilities:

The PI is responsible for the conduct of the study. Please review these responsibilities described at: <http://irb.ufl.edu/irb01/researcher-information/researcherresponsibilities.html>

Important responsibilities described at the above link include:

- Using currently approved consent form to enroll subjects (if applicable)
- Renewing your study before expiration
- Obtaining approval for revisions before implementation
- Reporting Adverse Events
- Retention of Research Records
- Obtaining approval to conduct research at the VA
- Notifying other parties about this project's approval status



cc:

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Informed Consent

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016

 Department of Veterans Affairs	VA RESEARCH CONSENT FORM
<p>Subject Name: _____ Date: _____</p> <p>Title of Study: <u>Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and Afghanistan</u></p> <p>Principal Investigator: <u>Bina Patel, LCSW</u> VAMC: <u>North Florida/South Georgia Veterans Health System</u></p>	
 Institutional Review Board UNIVERSITY of FLORIDA	
<p><i>INFORMED CONSENT FORM</i> <i>to Participate in Research</i></p>	
<p>INTRODUCTION</p>	
<p>Name of person seeking your consent: Bina Patel, LCSW</p> <p>Place of employment & position: NFSG VA Medical Center, Caregiver Support Coordinator, Social Worker</p> <p>Please read this form which describes the study in some detail. A member of the research team will also describe this study to you and answer all of your questions. Your participation is entirely voluntary. If you choose to participate you can change your mind at any time and withdraw from the study. You will not be penalized in any way or lose any VA or other benefits to which you would otherwise be entitled if you choose not to participate in this study or to withdraw. If you have questions about your rights as a research subject, concerns, complaints, wish to discuss problems or talk to someone independent of the research staff, obtain information, or offer input, please call either of the following offices: (1) the University of Florida Institutional Review Board (IRB) office at (352) 273-9600; or (2) the North Florida/South Georgia Veteran's Health System Research Service Office at (352) 374-6069.</p>	
IRB Project #: 201400365 IRB Version: 10/19/2011 PI Version: 9/22/2014	Page 1 of 9 VA Form 10-1086



Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016

 Department of Veterans Affairs	VA RESEARCH CONSENT FORM
<p style="text-align: right;">  </p>	
Subject Name: _____ Date _____	
Title of Study: <u>Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and Afghanistan</u>	
Principal Investigator: <u>Bina Patel, LCSW</u>	VAMC: <u>North Florida/South Georgia Veterans Health System</u>
<div style="border: 1px solid black; padding: 5px; width: fit-content; margin: 0 auto;"> GENERAL INFORMATION ABOUT THIS STUDY </div>	
<p>1. Name of Participant ("Study Subject")</p> <p>_____</p>	
<div style="border: 1px solid black; padding: 5px;"> <p>For PI Use:</p> <p>Participant Social Security Number: _____</p> <p>SSN should be written on this consent form by the research team prior to scanning into the VHA health record; if the subject does not have a VHA health record, this requirement is N/A.</p> </div>	
<p>2. What is the Title of this research study?</p> <p>Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and Afghanistan</p>	
<p>3. Who can you call if you have questions concerns, or complaints about this research study?</p> <p>Principal Investigator: Bina Patel, LCSW</p>	
<p>4. Who is paying for this research study?</p> <p>The sponsor of this study is the Department of Veterans Affairs</p>	
<p>5. Why is this research study being done?</p> <p>The purpose of this research study is to explore caregivers experiences in caring for a Veteran with serious invisible injuries from Iraq/Afghanistan and to determine some of the causes of caregiver burden as well as the positives of caregiving.</p> <p>You are being asked to be in this research study because you have been identified as a caregiver of a Veteran who was seriously injured in Iraq and/or Afghanistan.</p>	
IRB Project #: 201400365 IRB Version: 10/19/2011 PI Version: 9/22/2014	Page 2 of 9 VA Form 10-1086

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and AfghanistanPrincipal Investigator: Bina Patel ,LCSW VAMC: North Florida/South Georgia Veterans Health System

WHAT CAN YOU EXPECT IF YOU PARTICIPATE IN THIS STUDY?

6. What will be done as part of your normal clinical care (even if you did not participate in this research study)?

Normal clinical care is medical or other treatment or services that you would receive even if you did not participate in this research study. Your normal clinical care will not be affected or change based on your decision regarding this study.

7. What will be done only because you are in this research study?

You, as a Caregiver, will be asked to complete an interview either at your home or an agreed upon private location that should last approximately 90-120 minutes. If an additional follow up interview is required and cannot be completed via telephone this will be arranged at your convenience at your home or at an agreed upon private location. The interview will be recorded with an encrypted digital voice recorder that only the researcher will have access to and it will be secured with a password which only the researcher will be privy to. Interview questions are focused on your experiences as a caregiver and include questions about: Family characteristics and wellbeing, caregiver experiences, caregiver burden, social support, the Caregiver Support Program, and social media. Your identifying information will remain confidential as you will be assigned a numeric identifier in place of using your name and only the researcher will have knowledge of your identity.

The Principal Investigator listed in question 3 of this form and the research team conducting the research procedures described above will monitor how you do during the interview. If you have any questions about the research procedures now or at any time during the study, please contact one of the research team members listed in question 3 of this form.

8. How long will you be in this research study?

You will be in in this study for a period of one year or less.

9. How many people are expected to take part in this research study?

Approximately nine to 20 participants will be a part of the Caregiver Interviews.

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date: _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and AfghanistanPrincipal Investigator: Bina Patel, LCSW VAMC: North Florida/South Georgia Veterans Health System

WHAT ARE THE RISKS AND BENEFITS OF THIS STUDY AND WHAT ARE YOUR OPTIONS?

10. What are the possible discomforts and risks from taking part in this research study?

Possible risks may include emotional and psychological stress when describing your experiences as a caregiver. Should you experience any emotional or psychological stress the researcher will provide you with appropriate VA resources for counseling and support if needed, including individual counseling, a peer support mentor, support group referrals and telephone/online support groups. Should you disclose any concerns or fears of being hurt or abused, appropriate resources will be provided to including resource information about local shelters. Should you disclose any potential threats, abuse, or neglect towards children in the home, a report to the local child welfare agency will be initiated by the researcher.

Researchers will take appropriate steps to protect any information they collect about you. However there is a slight risk that information about you could be revealed inappropriately or accidentally. Depending on the nature of the information such a release could upset or embarrass you, or possibly even affect your insurability or employability.

Participation in more than one research study or project may further increase the risks to you. If you are already enrolled in another research study, please inform one of the research team members listed in question 3 of this consent form or the person reviewing this consent with you before enrolling in this or any other research study or project.

Throughout the study, the researchers will notify you of any new information that may become available and might affect your decision to remain in this study. This includes, but is not limited to, information that may affect your safety, well-being or medical care.

If you wish to discuss the risks or discomforts described above or any discomforts you may experience, please ask questions now or call one of the research team members listed in question 3 of this form.

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and AfghanistanPrincipal Investigator: Bina Patel ,LCSW VAMC: North Florida/South Georgia Veterans Health System**11a. What are the potential benefits to you for taking part in this research study ?**

You may feel a sense of relief that someone is researching how caregiving impacts you and your family.

11b. How could others possibly benefit from this study?

Providers and other caregivers will become aware of the issues that caregivers of Veterans who were injured in Iraq and Afghanistan are facing on a day to day basis. These factors may be incorporated into services that caregivers need as well as future research to help alleviate some of your caregiver related stress and to provide more targeted interventions.

11c. How could the researchers benefit from this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator listed in question 3 may benefit if the results of this study are presented at scientific meetings or in scientific journals. This research is also one part of the PI's graduation requirements in order for the PI to receive a doctoral degree in Social Work, therefore the research will be used to fulfill the PI's PhD dissertation requirements.

12. What other choices do you have if you do not want to be in this study?

You can share your experiences with local congressman or other researchers that maybe interested in studying your caregiver experiences.

13a. Can you withdraw from this study?

You are free to withdraw your consent and to stop participating in this study at any time. If you do withdraw your consent, you will not be penalized in any way and you will not lose any benefits to which you are entitled.

If you decide to withdraw your consent to participate in this study for any reason, please contact one of the research team members listed in question 3 of this form. They will tell you how to stop your participation safely.

If you have any questions regarding your rights as a research subject, please call the Institutional Review Board (IRB) office at (352) 273-9600.

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and AfghanistanPrincipal Investigator: Bina Patel, LCSW VAMC: North Florida/South Georgia Veterans Health System**13b. If you withdraw, can information about you still be used and/or collected?**

If you withdraw from this study, your research information will no longer be collected. However, information that has already been collected will continue to be used to the extent that the researchers have used it in this research study.

13c. Can the Principal Investigator withdraw you from this study?

You may be withdrawn from the study without your consent for the following reasons:

- If you are unable to proceed with the interview due to emotional distress and the Principal Investigator feels it would not be in your best interest to proceed with the study.

WHAT ARE THE FINANCIAL ISSUES IF YOU PARTICIPATE?**14. If you choose to take part in this research study, will it cost you anything?**

There will be no costs to you for any procedure, treatment or testing done as part of this research study. However, medical care and services provided by the VA that are not being done only for this study (e.g., normal hospital and prescription expenses which are not part of the research study) will be charged to you or your insurance. These costs may not be charged if you are a veteran and you are being treated at the North Florida/South Georgia Veterans Health System (NF/SG VHS), however some Veterans are required to pay co-payments for medical care and services provided by the VA. These co-payment requirements will continue to apply to VA-provided medical care and services that are not part of this study.

15. Will you be paid for taking part in this study?

No, you will not be reimbursed for participation in this study.

16. What if you are injured because of the study?

If you experience an injury or illness as a result of your participation in this VA approved research study, all medical treatment considered necessary by your physician (emergency as well as medical treatment beyond emergency) will be provided by the VA. There will be no cost to you, unless you fail to follow the

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and AfghanistanPrincipal Investigator: Bina Patel, LCSW VAMC: North Florida/South Georgia Veterans Health System

directions of the study procedures. Care will be provided at a VA medical facility unless the VA medical facility is not capable of providing the care. If this occurs, you will be treated by a private facility or physician and the VA will pay the private facility or physician for the reasonable cost of your care. In some cases the VA may approve private care for a non-veteran.

If you do not follow study procedures, you may be treated by the VA on the basis of your veteran's eligibility. If you are not a veteran and have not followed study procedures the VA can only provide limited care at your expense.

No additional money has been set aside for pain, suffering or any money losses you may suffer during your treatment. You have not waived any legal rights by signing this form.

In the event of a research-related injury, have questions about any discomforts that you experience while participating in this study or if you experience an adverse reaction, please immediately contact the Principal Investigator listed in question 3 of this form during the day and 386-623-4187 after business hours. If you seek emergency hospitalization in a private hospital because you are unable to come to the VA, have a family or friend contact your study doctor so that the VA can coordinate care with the private hospital.

17. How will your privacy and the confidentiality of your research records be protected?

Information collected about you will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the legal right to review these research records, and they will protect the secrecy (confidentiality) of these records as much as the law allows. These people include the researchers for this study, certain University of Florida officials, the hospital or clinic (if any) involved in this research, and the Institutional Review Board (IRB; an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research). Certain federal agencies such as the Office for Human Research Protections (OHRP), the VA Office of Research Oversight (ORO), or the VA Office of the Inspector General (OIG), that oversee human subject research may also have the legal right to review your records. Otherwise your research records will not be released without your permission unless required by law or a court order.

Researchers will take appropriate steps to protect any information they collect about you. However there is a slight risk that information about you could be revealed inappropriately or accidentally. Depending on the nature of the information such a

Study ID:IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and Afghanistan

Principal Investigator: Bina Patel ,LCSW VAMC: North Florida/South Georgia Veterans Health System

release could upset or embarrass you, or possibly even affect your insurability or employability.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

Study ID: IRB201400365 Date Approved: 9/30/2015 Expiration Date: 9/30/2016



Department of Veterans Affairs

VA RESEARCH CONSENT FORM



Subject Name: _____ Date _____

Title of Study: Caregivers of Veterans with Serious "Invisible" Injuries from Iraq and Afghanistan

Principal Investigator: Bina Patel, LCSW VAMC: North Florida/South Georgia Veterans Health System

SIGNATURES

As an investigator or the investigator's representative, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Signature of Person Obtaining Consent Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You have received a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting Date

VHA HIPPA Authorization

Department of Veterans Affairs		Authorization for Use & Release of Individually Identifiable Health Information for Veterans Health Administration (VHA) Research	
Subject Name (Last, First, Middle Initial):	Subject SSN (last 4 only):	Date of Birth:	
VA Facility (Name and Address):			
VA Principal Investigator (PI):		PI Contact Information:	
Study Title:			
Purpose of Study:			
<p>USE OF YOUR INDIVIDUALLY IDENTIFIABLE HEALTH INFORMATION (IIHI):</p> <p>Your individually identifiable health information is information about you that contains your health information and information that would identify you such as your name, date of birth, or other individual identifiers. VHA is asking you to allow the VA Principal Investigator (PI) and /or the VA research team members to access and use your past or present health information in addition to new health information they may collect for the study named above. The investigators of this study are committed to protecting your privacy and the confidentiality of information related to your health care.</p> <p>Signing this authorization is completely voluntary. However, your authorization (permission) is necessary to participate in this study. Your treatment, payment, enrollment, or eligibility for VA benefits will not be affected, whether or not you sign this authorization.</p> <p>Your individually identifiable health information used for this VA study includes the information marked below:</p> <p><input type="checkbox"/> Information from your VA Health Records such as diagnoses, progress notes, medications, lab or radiology findings, etc.</p> <p><input type="checkbox"/> Specific information concerning:</p> <p style="padding-left: 40px;"><input type="checkbox"/> alcohol abuse <input type="checkbox"/> drug abuse <input type="checkbox"/> sickle cell anemia <input type="checkbox"/> HIV</p> <p><input type="checkbox"/> Demographic Information such as name, age, race, etc.</p> <p><input type="checkbox"/> Billing or Financial Records</p> <p><input type="checkbox"/> Photographs, Videotapes, and/or Audiotapes of you</p> <p><input type="checkbox"/> Questionnaire, Survey, and/or Subject Diary</p> <p><input type="checkbox"/> Other, as immediately described below:</p>			

Authorization for Use & Release of Individually Identifiable Health Information for Veterans Health Administration (VHA) Research		
Subject Name (Last, First, Middle Initial):	Subject SSN (last 4 only):	Date of Birth:
<p>USE OF YOUR DATA OR SPECIMENS FOR OTHER RESEARCH: (This section must only be completed when banking is a required component of this study. When banking is an optional component of this study complete page 5 of this form in lieu of this section.)</p> <p><input type="checkbox"/> Not Applicable - No Data or Specimen Banking for Other Research</p> <p>An important part of this research is to save your</p> <p><input type="checkbox"/> Data</p> <p><input type="checkbox"/> Specimen</p> <p>in a secure repository/bank for other research studies in the future. If you do not agree to allow this use of your data and/or specimen for future studies approved by the required committees, such as the Institutional Review Board, you will not be able to participate in this study.</p> <p>DISCLOSURE: The VA research team may need to disclose the information listed above to other people or institutions that are not part of VA. VA/VHA complies with the requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), Privacy Act of 1974 and all other applicable federal laws and regulations that protect your privacy. The VHA Notice of Privacy Practices (a separate document) provides more information on how we protect your information. If you do not have a copy of the Notice, the research team will provide one to you. Giving your permission by signing this authorization allows us to disclose your information to other institutions or persons outside the VA/VHA as noted below. Once your information has been disclosed outside VA/VHA, it may no longer be protected by federal laws and regulations and might be re-disclosed by the persons or institutions receiving the information. These non-VA/VHA institutions or persons include the entities marked below:</p> <p><input type="checkbox"/> Non-VA Institutional Review Board (IRB) at _____ who will monitor the study</p> <p><input type="checkbox"/> Study Sponsor (name): _____ Person or entity who takes responsibility for and initiates a clinical investigation</p> <p><input type="checkbox"/> Academic Affiliate (institution/name/employee/department): _____ A relationship with VA in the performance of this study</p> <p><input type="checkbox"/> Compliance and Safety Monitors: _____ Advises the Sponsor or PI regarding the continuing safety of this study</p> <p><input type="checkbox"/> Other Federal agencies required to monitor or oversee research (such as FDA, OHRP, GAO): _____ _____</p> <p><input type="checkbox"/> A Non-Profit Corporation (name and specific purpose): _____</p> <p><input type="checkbox"/> Other (e.g. name of contractor and specific purpose): _____ _____</p>		

Authorization for Use & Release of Individually Identifiable Health Information for Veterans Health Administration (VHA) Research		
Subject Name (Last, First, Middle Initial):	Subject SSN (last 4 only):	Date of Birth:
TO BE FILLED OUT BY THE SUBJECT		
<p>Research Subject Signature. This permission (authorization) has been explained to me and I have been given the opportunity to ask questions. If I believe that my privacy rights have been compromised, I may contact the VHA facility Privacy Officer to file a verbal or written complaint.</p> <p>I give my authorization (permission) for the use and disclosure of my individually identifiable health information as described in this form. I will be given a signed copy of this form for my records.</p>		
_____ Signature of Research Subject		_____ Date
_____ Signature of Legal Representative (if applicable)		_____ Date
<p>To Sign for Research Subject (Attach authority to sign: Health Care Power of Attorney, Legal Guardian appointment, or Next of Kin if authorized by State Law)</p>		
_____ Name of Legal Representative (please print)		_____ Date