

“It Transforms All of You”: Lived Experiences of Partners of Iraq Combat Veterans with
Traumatic Brain Injuries

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Dedication

To those who support and care for all who served in Operation Enduring Freedom
and Operation Iraqi Freedom.

Acknowledgements

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Abstract

Dissertation Abstract

Just over two million service men and women have been deployed to the wars in Iraq and Afghanistan over the past ten years. Conservative estimates suggest that nearly one fifth of those deployed sustain a blast induced mild traumatic brain injury (TBI). Nearly half of those in the service are married, meaning a large number of spouses unexpectedly find themselves navigating a “new normal” after their partner returns from combat with ongoing sequelae from a TBI.

Ultimately, a sizeable number of spouses of Iraq combat veterans with TBIs have found themselves in the role of caregiver. The large majority of them were unprepared to take on that role. They had a limited number of resources to assist them in understanding the “new normal” and to guide them through the process of obtaining quality health care for their veteran spouses and for themselves. The purpose of this study was to describe the lived experience of the wives of Iraqi veterans with TBIs such that appropriate interventions may be crafted to support them in their role of caregiver.

A phenomenological approach was used to interview seven spouses of veterans who had a TBI from their military service in Operation Iraqi Freedom. A purposeful, snowball, networking technique was used to identify the study participants who met with a single researcher for one face-to-face interview lasting between 30 and 90 minutes. The interview narratives were analyzed for meaning units and subsequently five figural themes were identified: Change and Difference, Making Sense, Redefinition, Alone, and Commitment-Perseverance. The contextual ground for the five figural themes was one of Shifting Sands. The predominant experiences of the participants took place against in the existential element of Others. The

findings suggest multiple possibilities for the provision of structured support for spouses as they provide care for their recovering veteran partners.

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CHAPTER 1

Introduction

When I first began working as a nurse care manager in the Polytrauma Clinic at the Veterans Affairs Tennessee Valley Healthcare System (VA) in 2008, I envisioned it as an opportunity to be part of an interdisciplinary team providing care to a diverse group of veterans who had served in the wars in Iraq and Afghanistan. At that time, I had a basic understanding of the complex health care needs of those with combat acquired injuries, traumatic brain injuries (TBI) in particular. What I did not anticipate was my exposure to another diverse group of individuals looking for help and a minimal level of care: the spouses, girlfriends, boyfriends, and committed partners of the veterans. Over time, it became clear to me that if I was going to provide quality comprehensive nursing care to the veterans with TBIs, I had to find a way to provide some level of support to their partners. Many days it seemed as if the most pressing need of a veteran was to come up with information and services for their partner such that the partner could find a way to continue caring for the veteran in their shared home. Surprisingly, it was not just the very small group of partners caring for severely wounded veterans that needed attention. It was the multitude of men and women who were trying to keep a job, raise small children, and provide direction for their veteran partner who could not remember when to take their medications or which way to turn for the grocery store when they reached the end of the driveway. The majority of veteran partners knew few, if any, others in their same situation, facing the same struggles. They had an insufficient number of places to turn for help, few people in their lives who understood what their day-to-day existence entailed, and virtually no idea of what lay ahead for themselves and their families.

Prior to working as a nurse in the Polytrauma Clinic, I spent six years working at the medical center as a chaplain and as an addiction therapist. My work gave me the chance to interact with a diverse group of veterans and their families across a variety of settings in the health care system. I was continually exposed to small slices of military culture; a novel experience for me. Fairly early on, I served as the chaplain in a VA addiction treatment program working with a large population of homeless veterans. It did not take long to figure out that many in the VA substance abuse treatment program had significant underlying mental health issues. What took longer to understand was that many of the veterans in the program had untreated, combat related mental health disorders such as posttraumatic stress disorder (PTSD). Whether it was from serving in Desert Storm or Vietnam or WWII, the veterans' mental health issues did not melt away on their own following separation from the military; they simply resurfaced with a vengeance down the road. The veterans now had three problems instead of one; they were homeless, addicted, and still had the underlying mental health problems. For many, the abuse of drugs and alcohol was a means of self-medication for the demons that accompanied them home from the wars.

It came as no surprise that once I started working in the Polytrauma Clinic, I began to view the potential long-term mental health and neurocognitive disorders of the combat veterans from Iraq and Afghanistan as a public health catastrophe waiting to happen. The veterans were struggling to understand the lingering impact of their injuries and most were fully engaged in receiving care for the same. Meanwhile, their partners were working overtime to try and keep their loved ones engaged in a "new life", formed and shaped as the couple left the military culture. For a number of couples, the reintegration taking place back in their home communities

was equally or more stressful than the many months of deployment with one of them in a combat zone.

My desire to provide some level of care for the veterans' partners was not so much an epiphany, but a keen grasp of the obvious. If the veterans in my case load were going to continue to live at home, their partners needed to have some sort of assistance to relieve them of their ongoing caregiver burden. I did not want to be providing care for the Iraq veteran ten years from now in the VA Homeless Program or in the substance abuse treatment program. I wanted to find a way to support those who support those who served.

When I left my position in the Polytrauma Clinic in late 2009, the Department of Veterans Affairs had not yet devised a system of assessment and interventions designed specifically to assist those who are living in committed relationships with the men and women who served our country in Iraq and Afghanistan. The Caregivers and Veterans Omnibus Health Services Act of 2010 was signed into law in May of 2010 a few months after I left the VA. The new law was public acknowledgement that the caregivers of veterans were in need of additional assistance. Yet, at this point in time, very little research remains regarding the longer term, post-acute care setting needs of the veterans' partners

When service members are deployed, a system of care and ready community exists for their partners. Structures for assistance range from the more formal Family Readiness Groups to the more informal online aid and information groups such as SpouseBUZZ. However, when a military service member separates from the military and returns to civilian life, the loss of support and care for military partners becomes part of the shift from military culture to civilian culture. In fact, when writing about serving families of veterans in the VA polytrauma system of care, Collins and Kennedy (2008) noted that patients and families experience a sense of true loss

as they leave the security and comfort of a medical military facility and move to a VA facility where there is less of a shared military culture.

I have worked with significant numbers of veterans transitioning from military life to civilian life, allowing me to grasp the scope of the potential difficulties for veterans and their partners as they make that transition. Particularly poignant is the challenge of the partner of a veteran with a mild to moderate TBI who continues to struggle with ongoing neurocognitive symptoms. In my caseload, I encountered countless partners of veterans with TBIs who expressed a strong desire to participate in the ongoing recovery of their veteran partner as well as find ways to care for themselves. As a provider, I wanted to offer them the skills, knowledge, and resources to do just that, but I was uncertain as to how best to meet their myriad needs for assistance. This research sought to answer the question of how to better meet the needs of the partners of veterans from the wars in Iraq and Afghanistan with a TBI by describing the lived experiences of their partners. In the end, all study participants had partners who were part of the military forces who went solely to Iraq, not Afghanistan.

In this chapter I describe a portion of the literature on civilian brain injuries and compare it with what is known regarding combat acquired TBIs. I present a brief summary of what is known regarding combat veterans who have a TBI acquired during their deployment to the wars in Iraq and Afghanistan. Following that, I briefly describe the VA system of care. Next, the focus turns to the potential consequences for veteran partners with four distinct areas of discussion: (a) partners' well-being, (b) caregiving, (c) burden and stress, and (d) family functioning. Subsequent to that will be a description of the economic cost of providing care to veterans and their families. All of the preceding is summarized prior to moving on the structure of the research study. The purpose of the research is stated as is a research question, and descriptions of

the constructivist perspective and the phenomenological approach to research. A definition of terms follow and the chapter concludes with the significance of the proposed research to the field of nursing.

Background

In October 2010, *The Washington Post* ran an extensive series titled “The Cost of War: Traumatic Brain Injury” with special reports titled “Coming Home a Different Person” and “It Changes Who We Are” (Davenport, 2010). Focusing on what the injury means for the veteran, the series built a case to support the statement made by a neuro-psychiatrist on the TBI unit at Bethesda Naval Center, Dr. Williamson who said, “When the brain is injured, it affects our humanity” (Davenport, 2010). He was referring to humanity as defined by “the qualities or characteristics considered as a whole to be characteristic of human beings” (Encarta World English Dictionary, 2009). Brain injuries impact multiple aspects of a veteran’s life and inescapably touch the life of the one closest to the veteran, their intimate partner. Life with a veteran who struggles with the physical, neurocognitive, and emotional consequences of a TBI changes the character of various features of an intimate relationship, as *The New York Times* writer Catrin Einhorn describes in her September 2011 article, “Looking After the Solider, Back Home and Damaged”. Einhorn (2011) quoted a veteran’s wife who states, “I felt like I went from this high-energy, force-to-be-reckoned-with businesswoman, to a casualty of war. And I was working furiously at not feeling like a victim of war”. As the prominence in the aforementioned leading national newspapers implies, there has been an upsurge in general awareness about veterans who returned from the wars in Afghanistan and Iraq with a TBI. Additionally, the Caregivers and Veterans Omnibus Health Services Act of 2010 was signed into law on May 6th of 2010, and in January of 2011 it became mandatory for all military branches to identify, treat,

and track any service member who had been within proximity of a blast (Weinberger, 2011). In short, recognition of one of the neglected invisible wounds of these wars, the TBI, is starting to gain momentum in public, military, research, and medical spheres. As new knowledge born of concerted research efforts is disseminated, critically important interventions and services for veterans will likely be implemented. However, outside of the public sphere, the chasm surrounding knowledge regarding the impact the veterans' TBI has on the lives of their committed partners continues to grow.

Civilian vs. Military Brain Injuries

Mechanics. The civilian brain injury literature highlights the challenges faced by the intimate partners of individuals with acquired brain injuries. One would expect to find similarities between the intimate partners of civilians with impact related TBIs and the experiences of intimate partners of combat veterans with TBIs sustained primarily from a blast. Yet, early studies are identifying significant distinct differences in the nature of sequelae experienced by the two groups, suggesting the importance of the cause of the injury; impact or blast (French & Parkinson, 2008; Terrio et al., 2009). The scientific literature continues to highlight the lack of conclusive evidence regarding similarities in post TBI adjustment between those who acquired a TBI in the civilian sector and military service personnel with combat acquired TBIs (Polusny et al., 2011).

The Institute of Medicine [IOM] (2010) describes the nature of combat acquired brain injuries and the frequency of those injuries as distinctly different from the brain injuries incurred by civilians. For example, the physiology of the injury itself differs between the two groups. Whereas the majority of civilian impact brain injuries are a one-time event, military service members in the current wars are more likely to have repeated mild blast TBIs from exposure to

multiple improvised explosive devices and rocket propelled grenades (Tanielian & Jaycox, 2008). Over 60% of combat acquired TBIs are a result of exposure to pressurized blast forces which produce an overpressurization wave with the velocity and strength to cause an interaction between the wave and the body, rendering a level of injury to the brain (Defense Manpower Data Center, 2010; Meyer, Helmick, Doncevic, & Park, 2008; Terrio et al., 2008).

Cutting-edge research exploring the mechanics of blast injuries has revealed a unique chain of events on the cellular level, which differs from the TBIs most frequently seen in the civilian population. Essentially, during a blast-induced brain injury, the cerebrovasculature undergoes an initial vasospasm which sets off a cellular chain reaction, resulting in a disturbance in the integrin signaling process between the brain's neurons (Alford et al., 2011). The types of blast injuries seen in Iraq and Afghanistan are primarily related to the widespread use of improvised explosive devices (IED). Over time, service members are potentially exposed to multiple small IEDs, returning home with no visible physical injuries, but a constellation of relentless symptoms ranging from angry outbursts to memory problems. Theoretical models indicate that the delayed clinical symptoms of mild blast-related TBIs may be related to local ischemia caused by acute vasospasms in the brain. Additionally, scientists are discovering that the altered role of integrin, a transmembrane protein, adds to the injury pathway causing the diffuse axonal injuries seen in mild TBIs (Alford et al., 2011; Hemphill, et al., 2011). The Armed Forces Health Surveillance Center (2011) data for TBIs in the military over the past ten years indicate that more than 75% of TBIs are classified as mild TBIs (mTBI), most from IEDs and similar types of high powered blasts (IOM, 2010). The critical piece in the blast vs. impact TBI discussion is the finding that military personnel returning home with combat acquired TBIs are more likely to have an unknown trajectory of longer term neurocognitive and psychological

dysfunction disrupting their social relationships, living situations, and potential for employment (IOM, 2009). Therefore, it cannot be assumed that the research and subsequent literature on civilians with brain injuries transfers to those with combat acquired TBIs. Nor can it be assumed that literature on partners of civilians with brain injuries transfers to the partners of those with combat acquired TBIs.

TBI. The prevalence of TBIs among returning Iraq and Afghan combat soldiers has resulted in the TBI acquiring the label of the “signature injury” of the wars in Afghanistan and Iraq (Tanielian & Jaycox, 2008). Injuries caused by improvised explosive devices were responsible for 26,724 major injuries to date, greater than 62% of all reported injuries between October of 2001 and March of 2010 (Defense Manpower Data Center, 2010). Those figures do not include moderate or mild TBIs which may leave no visible injury at the time of the explosion. Given that closed head injuries have no outward physical symptoms to identify them as such and many of the TBIs caused by IEDs are mild, they cause no immediate or alarming symptoms post-injury. There are currently a multitude of ongoing scientific research studies attempting to identify the percentage of combat veterans with persistent TBI-like symptoms from previously unrecognized and untreated mild TBIs from exposure to improvised explosive devices or rocket propelled grenades while in Iraq or Afghanistan. The nonprofit research institution, the RAND Corporation, supported a research study which utilized a large randomized sampling technique with weighted adjustments and stratified protocol (Tanielian & Jaycox, 2008). The reported results place the prevalence of TBIs in the returning veterans at 19%. A study conducted by Terrio et al. (2009) focusing on one combat brigade places the percentage of those with mild TBIs at 23%. Griffin and colleagues (2011) suggest that “at least 22%” of

soldiers in combat return home with some level of TBI and many have additional injuries if their TBI was the result of an IED.

Accurate data regarding combat acquired TBIs remains difficult for members of the general public, including researchers at NIH, to obtain (Weinberger, 2011). Among other reasons, one of the difficulties in tracking combat acquired TBIs is the more than 50% of military service members who, once separated, do not receive their care through the VA or military system. This limits the availability of data regarding the prevalence of diagnoses (Carlson et al., 2010; Jordan, 2011; Tanielian & Jaycox, 2008). Additionally, many of the post concussive symptoms mirror those of other conditions of combat, including posttraumatic stress disorder and major depressive disorder, which introduces the possibility that providers may not be accurately diagnosing mild to moderate TBIs (Jordan, 2011).

The Armed Forces Health Surveillance Center reports that between January of 2002 and December of 2011 a diagnosis of TBI was given to 210,632 military service personnel in the Military Health System (Defense and Veteran Brain Injury Center [DVBIC], 2012). Of particular interest is the fact that the preceding figure does not include individuals who were diagnosed with a TBI after they separated from the military and are either receiving care through the Veterans Affairs Health Care System or through private providers. Additionally, the Military Health System figure of 210,632 includes all sources of brain injuries, not just combat acquired TBIs. However, the data does represent a solid figure reflecting the large numbers of veterans who have received care for some level of TBI over the past 8 to 9 years. It also means that close to 100,000 partners are likely adapting to changes in their life related to their veteran partner's TBI.

TBI and PTSD. Combat experiences in Iraq and Afghanistan have resulted in upwards of 40% of veterans with a cluster of residual symptoms known as posttraumatic stress disorder [PTSD] (Tanielian, & Jaycox, 2008). The link between PTSD and TBI in the conflicts in Iraq and Afghanistan is complex; with a greater than 40% overlap in the symptoms of the two suggest that veterans who acquired a TBI in the Iraq conflict are at greater risk of having PTSD. They found that 43.9% of soldiers who lost consciousness from a blast injury also met the diagnostic criteria for a PTSD diagnosis. Although there is variance in estimates of returning service members with PTSD and a TBI, Tanielian and Jaycox's (2008) review of 22 research studies concluded that close to 33% of veterans with probable TBIs were likely to meet the criteria for PTSD. It has been suggested that the impaired cognitive processes typical of those with a TBI have a poorly understood impact on the level of vulnerability to PTSD (French & Parkinson, 2008).

Recently published research conducted with a large sample from the United States Army looked at the interplay between mild TBIs, PTSD, and depression found that a veteran who sustains a TBI involving loss of consciousness is significantly likely to have accompanying PTSD (Hoge, 2008; Sayer, 2012; Wilk, Herrell, Wynn, Riviere, & Hoge, 2012). Individual studies found the comorbidity rates of PTSD and TBI among military service personnel to be between 32% to 66% with the bulk of studies putting the percentage of overlap at just around one third (Hoge, 2008; Sayer, 2012; Tanielian & Jaycox, 2008; Wilk, Herrell, Wynn, Riviere, & Hoge, 2012). However, a study looking specifically at veterans from the wars in Iraq and Afghanistan who sought care from the VA system in 2009 found that only 6.7% of veterans had a diagnosis of TBI (Taylor et al., 2012), but of those 73% had a concurrent diagnosis of PTSD.

The current research suggests a number of possibilities for the yet to be defined high comorbidity between TBI and PTSD: (a) TBI and PTSD are a result of the combat event of experience itself; (b) neurological damage from the TBI predisposes the soldier to acquiring PTSD; (c) multiple deployments create multiple opportunities to acquire a TBI and PTSD essentially independent of one another (Sayer, 2012; Wilk et al., 2012). The continued focus on studies which examine the relationship between PTSD, TBI, and post deployment health issues is imperative for reasons which range from targeting appropriate evidence based treatment to the provision of early intervention for the correctly diagnosed health disorder (Polusny et al., 2011).

System of care. As mentioned earlier, blasts and explosions have come to be the most frequent mechanism of injuries sustained by military service members in the current wars (Meyer et al., 2008). While in the military, all active duty service members and their families receive their health care through the Department of Defense Military Health System (MHS) which is comprised of a number of sophisticated rehabilitation facilities, top notch trauma centers, 400 comprehensive clinics, and 70 hospitals, both on bases in the United States and abroad (Tanielian & Jaycox, 2008). When active duty service members complete their time in the military and conclude the discharge process, neither the veterans nor their families are eligible to continue to receive care within the MHS, but must begin to receive their health care outside of the military system. All members of the military who served in combat in either Iraq or Afghanistan are eligible for five years of free health care in the VA health care system for any condition related to their time in the combat theatre. The five-year eligibility period begins the day of their discharge from the service (United States Department of Veterans Affairs, 2011a). Veterans' families are not eligible to receive ongoing health care in the VA system. Currently, less than 50% of veterans utilize the VA system for their care, choosing to receive their care

through a private provider or not seeking care at all (Tanielian & Jaycox, 2008). Community Vet Centers, stand-alone clinics providing readjustment counseling services and staffed by VA personnel, are available to both combat veterans who received a military campaign ribbon and their family members (VA, 2010).

Consequences for Partners

The long-term sequelae of clinically diagnosed TBIs include a wide variety of symptoms which impact the day-to-day lives of the injured individuals and potentially have a subsequent impact on their partners. The most common long-term symptoms of TBIs include some combination of memory and concentration problems, headaches, impaired executive functioning, irritability, anxiety, fatigue, pain, and balance difficulties (Carlson et al., 2010; Griffin et. al., 2009). The civilian brain injury literature indicates that committed partners find themselves adjusting to changes in partnered life, including but not limited to, significant role shifts, loss of emotional support and companionship, decrease in parenting assistance, financial strain, decrease in social opportunities leading to increase in isolation, possible loss of empathetic communication, and alteration of sexual intimacy (Blais & Boisvert, 2005; Chronister & Chan, 2006; Chwalisz, 1996; Knight, Devereus, & Godfrey, 1998; Sinnakaruppan, Downey, & Morrison, 2005). Research on the partners of veterans from previous wars struggling with emotional and neurocognitive injuries, such as PTSD, indicates that the intimate partners are at greatly increased risk for stress, anxiety, caregiver burden, and distress resulting in both the veterans and their partners coping with ongoing psychological adjustments (Calhoun, Beckham, & Bosworth, 2002; Dekel, Goldblatt, Keidar, Solomon, & Polliack, 2005).

Like other combat veterans before them, Iraq and Afghan veterans' neurocognitive symptoms affect multiple aspects of their lives, not the least of which is their relationships with

their spouses or partners (IOM, 2010). Over time, the personal price of a combat acquired TBI becomes a shared burden (Karnery & Crown, 2007). Statistics from late 2009 indicate that of the 1.9 million OEF/OIF veterans, close to 52% are legally married (IOM, 2010). There are no available statistics on the number of service members who have a domestic partner. The most conservative estimates suggest that 15-20% of service members are returning home with some level of TBI (Tanielian & Jaycox, 2008). At the very least, that means 100,000 partners will be sharing the burden of a veteran's TBI which for some, leads to significant distress and subsequent social isolation (Arzi, Solomon, & Dekel, 2000; Collins & Kennedy, 2008; Dausch & Saliman, 2009; Jordan, 2011).

Partner well-being. When writing about the lives of spouses and partners of military service members, Eaton and her colleagues (2008) point out a variety of fairly exceptional stressors which range from a mobile lifestyle to the heightened uncertainty and anxiety when the service member is deployed to a combat zone. In the current wars, prolonged and multiple deployments are not uncommon, wearing on soldiers and spouses alike (Eaton et al., 2008; Mansfield et al., 2010). Studies are emerging that demonstrate the impact of prolonged deployments on the mental health of wives of U.S. Army service members. Overall, spouses of deployed service members seek mental health services for anxiety, depression, acute stress reactions, and sleep disorders at a significantly higher rate than those whose partners are not deployed (Mansfield et al., 2010). When service members return home, their partners may find themselves simultaneously coping with reintegration and preparing for the next deployment. In some cases, it becomes a matter of traumatized soldiers returning to partners who are worn and traumatized themselves from the stress and strain of coping with the soldier's absence in a combat zone (Hutchinson & Banks-Williams, 2006). The level of increased stress seen in

military family members during periods of deployment poses potential disruptions to the long-term health and well-being of those families (Mansfield et al., 2010). The risks of substance abuse, lingering depression and anxiety, marital discord, and continued levels of extreme stress can become all too real for partners who find themselves trying to cope with the war time trauma of their veteran partner (Collins & Kennedy, 2008; Coza et al., 2010; Manguno-Mire et al., 2007). The impact that combat acquired PTSD has on the psychological well-being of a veteran's partner has shown to be significant (Galvoski & Lyons, 2004). It remains to be seen if research on combat acquired TBIs suggests that the impact on partners is similar to that of PTSD. However, the known effect of a veteran's PTSD on the mental health of their partner, coupled with the evidence of distress in the partners of civilians with TBIs, suggests that continued focus on the mental health and well-being of veteran partners is warranted. There may well be a need to create interventions to care for those partners most likely to be at risk from the negative consequences of a veteran's TBI (Tanielian & Jaycox, 2008).

Caregivers. The majority of research literature on civilian brain injuries uses the term "caregiver" to refer to family members who live with brain injured individuals. The same term appeared in only a limited fashion in the research about veterans from the wars in Iraq and Afghanistan up until the past 12 to 18 months when "caregiver" began to appear more frequently in the literature. The use of the word "caregiver" in the May of 2010 Caregivers and Veterans Omnibus Health Services Act suggests that the term may find greater traction in the research literature from this point forward. The June 2010 National Defense Health Board's *Becoming a Family Caregiver for a Service Member/Veteran with TBI* defines caregiver as follows: "Any family or support person(s) relied upon by the service member or veteran with traumatic brain injury (TBI) who assumes primary responsibility for ensuring the needed level of care and

overall well-being of that service member or veteran.” Important to note, the parameters of post-injury caregiving have not yet been established for the Iraq and Afghanistan combat injured military population, as the type and amount of long-term care necessary for those individuals remains unknown at this time.

Burden and stress. The role of subjective burden and stress in the lives of partners of individuals with TBIs has been studied extensively in civilian brain injury literature. Civilian brain injury researchers frequently use the concept of caregiver burden and operationalize it as differing combinations of stress, depression, anxiety, social support, emotional distress, quality of life, or coping (Blais & Boisvert, 2005; Degeneffe, 2001; Knight et al., 1998). Caregiver burden is just beginning to appear in the research literature in reference to the partners of Iraq and Afghan combat veterans with neurocognitive deficits, with the majority of studies focused on PTSD as opposed to TBI (Caska & Renshaw, 2011; Manguno-Mire et al., 2007). The contribution of burden, stress, anxiety, depression, social support, emotional distress, and subsequent coping on the overall adjustment and well-being of partners of Iraq and Afghanistan war veterans has been discussed in relationship to deployment, posttraumatic stress disorder, and post-deployment (Galovski & Lyons, 2004; Goff, Crow, Reisbig, & Hamilton, 2007; Renshaw, Rodrigues, & Jones, 2008; Sherman et al., 2005). In each case, perceived caregiver burden was associated with the overall psychological well-being of veteran partners. This early research affirms the evidence found in the discussion of the adverse effects of caregiver burden in the civilian TBI literature; caregivers possess a continuum of needs, and are susceptible to anxiety, depression, and high levels of stress (Degeneffe, 2001; Sinnakaruppan & Morrison, 2005). Additional studies indicate that continued burden is negatively associated with quality of life and optimal physical and mental health of the one providing care to the family member with a TBI

(Blake, 2008). There are social consequences to caregiving which increase the burden and decrease the availability of social support systems, increase isolation, and contribute to the potential for subsequent psychological distress (Blais & Boisvert, 2005; Gill, Sander, Robins, Mazzei, & Struchen, 2011). The research overwhelmingly suggests that the caregiving burden related to a veteran returning from combat with an injury which has ongoing neurocognitive and emotional symptoms will be significant. There is ample evidence that understanding the burden of caregivers and devising interventions designed to reduce the perception of burden may improve the overall well-being and functioning of those providing care (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007; Hanks, Rapport, & Vangel, 2007).

Family functioning. Effective family functioning has been cited by Collins and Kennedy (2008) as an essential part of the recovery process for veterans with TBIs. Studies on family functioning and subsequent health outcomes among civilians with acquired TBIs affirm the assumption that brain injured individuals functioning as part of a healthy family system make greater progress in their long-term rehabilitation efforts (Dausch & Saliman, 2009). The quality of family functionality while an individual is in the military has a significant impact on the health outcomes and quality of life for all family members as service members transition to civilian life (Griffin, Friedemann-Sánchez, Hall, Phelan, & van Ryn, 2009). Overall, dysfunctional and struggling military families perpetuate the same methods of operating as they move from the military setting to a civilian one, while adding stressors during the transition. The process of veterans' reintegration after deployment generally follows a fairly predictable path which the majority of couples traverse at a measured pace, utilizing the same coping resources they employed during the period of deployment (Bowling & Sherman, 2008). Typically, couples need to renegotiate roles, alter existing responsibilities and expectations, reconnect with different

social networks, and adapt to personal changes that occurred during the period of deployment (Institute of Medicine of the National Academies, 2010).

The lingering symptoms of a TBI such as trouble with concentration and memory, anger, impulsivity, organization, and feelings of sadness tend to make the process of readjustment and reintegration into family more challenging for veterans than originally anticipated (Meyer, Helmick, Doncevic & Park, 2008; Tanielian & Jaycox, 2008). A study on family distress during the post-deployment period found that fully two-thirds of children and spouses experienced significant post-deployment family distress when a military family member returned from the war with a combat injury (Cozza et al., 2010). Not surprisingly, in a number of studies, wives exhibited greater levels of distress when they were unable to see their veteran husband's injuries and did not know the cause of their symptoms (Goff et al., 2007; Renshaw et al., 2008).

Cost

The "costs" of caring for a veteran with a TBI can be divided into multiple financial, social, family, and personal categories, the latter three of which have been touched on earlier in this chapter. The estimated financial cost of caring for individual service members with TBIs varies widely depending on the severity of the TBI, the source of medical care, and the presence of co-occurring disorders such as PTSD. However, Tanielian and Jaycox (2008) have created a model whereby they hypothesize a cost-of-illness estimate of \$591 to \$910 million as a reasonable conservative estimate of the 2005 deployment related TBI costs. One can reasonably assume that six years later, with more veterans being diagnosed with TBIs, the life time cost of providing ongoing medical care and VA disability payments will be much higher. A more current study estimates the VA health care cost for veterans from the Iraq and Afghan wars will be between \$7 and \$9 billion over a ten-year period, 2008-2017 (Goldberg, 2007). VA disability

payment projections range between \$68 and \$127 billion (Blimes, 2007). The preceding figures are estimates of the financial expenditures anticipated by government agencies, but not for the price of care in the private sector. Additionally, the ongoing costs of a combat acquired TBI not directly linked to treatment include loss of productive work time, possible substance abuse comorbidity, decreased quality of life, homelessness, fractured families, intimate partner violence, and suicide (Tanielian & Jaycox, 2008).

A recent study of the financial strain sustained by family caregivers of veterans who received care for a TBI at a VA Polytrauma Rehabilitation Center revealed that 36.8% of caregivers have left the work force and over half have either acquired debt or used personal assets to assist in paying for additional care for their veteran family member (Van Houtven, 2011). The author suggests that the financial strain borne by the caregiver acts as a barrier to the provision of optimal care to those veterans who were severely injured during the war. Of note is the fact that the Caregivers and Veterans Omnibus Health Services Act had just been signed into law when the Van Houtven (2011) study was presented. It is anticipated that the new law will ease some of the financial burden for families caring for the most severely injured as some family caregivers will qualify for direct monthly financial stipends (Griffin et al., 2011). The Omnibus Health Services Act will not, however, bring financial relief to those families who are struggling to provide quality on-going care for veterans who have significant, but less debilitating, symptoms. The magnitude of the personal cost to current and former military personnel and their families is so great that it is difficult to even begin to estimate.

Summary

Since October of 2001, nearly 2.2 million service men and women have been deployed to the war zones in Iraq and Afghanistan, leaving close to one million spouses at home awaiting their safe return (Karnery & Crown, 2007; Sayer, 2011). Most service members return home safely and resume their lives as spouses or partners, experiencing minimal difficulty with the adjustment process. However, estimates suggest that between 20 to 30% of service men and women will return home with a TBI (Tanielian & Jaycox, 2008). The lingering effects of a TBI on a soldiers' mental and cognitive functioning become the very impairments which have the greatest impact on their intimate partners. Difficulty with communication and interpersonal processes is part and parcel of the residual symptoms of TBIs (Griffin et al., 2011). Intimacy necessitates that each individual have the capability to monitor and express their own emotions, control impulses, look after one another's needs, and "be present." The lasting physical and mental health problems from a TBI impact the individuals involved in the partnership and are equally detrimental to the relationship (Goff et al., 2007). The health of a veteran's primary relationship impacts the veteran's reintegration into the civilian world (Dausch & Saliman, 2009). Focusing on promoting the health and well-being of veteran partners ultimate affects the veterans themselves.

The statistics on intimate partner violence (IPV) following deployment lends further credence to the pressing need for the crafting of supportive measures for the partners of veterans. While wide variation on prevalence rates exists in the literature, on the whole the prevalence of IPV in the military population is similar to that of the general civilian population if researchers compare matched sample sets (Marshall, Panuzio, & Taft, 2005). However, studies of veterans with ongoing difficulties controlling their impulses and emotions strongly suggest they have a

significant increase in the risk of IPV that far surpasses that of the civilian population (Jordan et al., 1992; Marshall et al., 2005). In the civilian brain injured population, aggressive behavior attributed to lack of impulse control has a direct link to the neurologic damage caused by a TBI (Kim, 2002). At this time, there are no published studies linking combat acquired TBIs to an increase in the prevalence of IPV, but the evidence suggests that the combination of neurocognitive injuries and potential war trauma sequelae would lead to just that. The partners of veterans with TBIs would be well served by a fundamental understanding of what resources and coping tools may facilitate their ongoing personal safety should their relationship begin to become abusive.

If the lessons learned from previous wars and the civilian brain injury community are an indication, it is past due time to begin focusing on the partners of veterans with a combat acquired TBI so that both the partner and the veteran can receive necessary services to function at optimal levels in all aspects of their lives.

Purpose Statement

The purpose of this phenomenological study was to describe the experience of partners of veterans with a TBI acquired during the war in Iraq at least two years prior to the study.

Research Question

This research sought to describe the experiences of partners of Iraq combat veterans with TBIs to assist with answering the following research question:

- What is the lived experience of the partners of Iraq war veterans with a TBI acquired during their deployment two or more years ago?

The question posed to the study participants in a face-to-face interview was, “As you think about your experiences over the past years, after your partner acquired a TBI, what stands out for you?”

Research Paradigm

Social constructivist. A social constructivist perspective was used to examine the proposed research question. Social constructivism calls attention to beliefs, behaviors, and truths as continually shaped by virtue of a person’s interactions with a specific culture and between individuals within the culture. In this manner, knowledge is not perceived as fixed, but as continually evolving. Miller, Kulkarni, and Kushner (2006), in writing on trauma work with war affected populations, suggest the social constructivism perspective is one that seeks not only to find what is “real” within a specific context, but it is also a perspective that promotes the exploring of various ways to describe and understand psychological health and distress within a specific cultural setting.

Creswell (2009) explains the social constructivist perspective as one that seeks to locate meaning in the context of the participants’ lives. He maintains that the goal of a social constructivist approach is to understand the meaning persons ascribe to their lives as they themselves live it within their unique personal, social, cultural, and historical experiences. In light of such, the researcher must explore relevant historical and social background factors as critical to the construction of meaning within a particular context. Social constructivist’s research questions are open-ended, general, and continually molded by the participants’ views. Reality exists and is described only in relationship to the individual experiencing it. Meaning does not exist independent of the perceptions of those living the reality of their distinct experiences.

Lauder, Anderson, and Barclay (2002) posit the medical model as the antithesis; it seeks to create a reality that confirms a specified truth congruent with its objectives.

The reality of partners of combat veterans with TBIs likely encompasses their prior lived experiences of being in relationship with a soldier who has been trained in what, until June of 2009, was referred to as Battlemind Training. The United States Army has since been renamed Battlemind Training as Resilience Training and describes it as “the soldier's inner strength to face fear and adversity with courage. Key components include (a) self-confidence: taking calculated risks and handling challenges and (b) mental toughness: overcoming obstacles or setbacks and maintaining positive thoughts during times of adversity and challenge” (U.S. Army Medical Command, 2009). The constructed character of such a reality appears to focus solely on the “warrior” at a particular juncture in time. The reality of the partner in this scenario is neither seen nor acknowledged. In essence, one is left to surmise that the reality of the warrior transcends the individual, becoming the reality of the partner by virtue of shared time and space. The social constructivist lens allows for the veterans’ partners, in their unique cultural context, to incorporate or disallow the prevailing Battlemind genre of the military.

Gergen (1996), who has written extensively on the use of social construction in psychology, calls for more focused attention on those who find themselves on the sidelines when there is a historical and cultural dominant understanding of experience which has been seen from a prevailing world view. In the case of partners of combat veterans with significant mental health difficulties, the dominant voice has been understood in terms of the assumptions and perspectives of the veteran-warrior with little regard for the caretaker-partner perspective. The existing reality of the veteran does not, in the social constructivism perspective, logically generate a framework that transfers to the partner.

Phenomenology. In seeking to understand the phenomena of living with a veteran with a TBI, the research question was studied using an interpretive phenomenological research method. When there is little known about a topic and the purpose of the research is to gain an understanding of the common experiences of a particular group of individuals interacting with a shared phenomenon, the phenomenological research approach is deemed as the best fit (Creswell, 2007). Phenomenology is grounded in the essence of individuals' reflections on their subjective experiences and their perceptions of the phenomenon of interest (Thomas & Pollio, 2002). This study sought to describe the essence of the experience of living with a veteran with a TBI acquired in the wars in Iraq. Phenomenology is known as a method, but is also a philosophy. For this study, the underlying philosophy was that of Merleau-Ponty, an existentialist who proposed the idea that human beings are formed by their experiences in the world, yet they also form their worlds through the choices they make in the context of their experiences (Sadala & Adorno, 2002).

Assumptions

1. Partners of veterans with combat acquired TBIs have a different caregiving experience than partners of civilians with TBIs.
2. Partners have different support needs, over time which have not been identified and are not being met.
3. The impact of caring for a veteran with a TBI is uniquely challenging, often requiring greater ongoing care from a partner.
4. The physical, emotional, and cognitive needs of the veteran have the potential to exceed the resources of the partner two or more years post-injury.

5. It is assumed that the process of describing the experience of the study participants will lead to knowledge which can then be used to better care for the Iraq and Afghanistan veterans by providing direct support for their partners.
6. Participants will be honest and forthcoming regarding their descriptions of their experiences of the past few years.

Limitations and Delimitations

The proposed research included only partners of veterans who sustained a TBI at least two years prior to the beginning of the research project. The limitation was important in that the long-term consequences of living with a veteran with a combat acquired TBI remain unknown. Partners of injured active duty military service members have access to a structured system of community and care in the time period immediately following an injury. As time goes on and service members separate from the military, finding the resources available for care and support typically becomes more of a challenge as services are not always readily available close to the veteran's home.

Partners of veterans with a TBI were included in the sample as were those whose partners may have coexisting disorders such as PTSD or depression. Partners of veterans with only PTSD were not included in the sample. The research literature contains an ample body of work on the experiences of partners of veterans with PTSD, but limited research exists on partners of veterans with a TBI. The participants had partners exclusively from the United States Army, but not the Army National Guard nor Reserve. Research has suggested that those in the Guard and Reserve have additional reintegration challenges which are uniquely different from those in the Army (Renshaw, Rodrigues, & Jones, 2008). The potential limitations of the study include its lack of generalizability to all partners of Iraq and Afghanistan war veterans with a TBI acquired

in combat, including members of other branches of the military. The use of the phenomenological method in qualitative research was to gain an understanding of the essence of the participant's lived experience which may or may not be generalizable to others experiencing similar phenomena in their lives (Creswell, 2007).

Definition of Terms

OEF/OIF/OND. On October 7, 2001, the United States began combat operations in Afghanistan in an operation formally known as Operation Enduring Freedom or OEF. For the purpose of this study, any soldier who served in the war in Afghanistan after September 11th, 2001, is considered an OEF veteran. On March 20, 2003, the United States Global War on Terror began its military campaign in Iraq, named Operation Iraqi Freedom or OIF. For the purpose of this study, soldiers who served in the war in Iraq from March of 2003 until August 31, 2010, were considered to be OIF veterans. The combat operations in Iraq officially ended on September 1, 2010. The military service members in Iraq after that time were considered part of Operation New Dawn (OND), focusing their efforts on stability operations with a focus on training and advising Iraq Security Forces.

Partner. For the purposes of this study, the term partner refers to either the legal spouse or the domestic partner of the veteran. The Human Rights Campaign defines a domestic partnership as, "two individuals who are in a long-term committed relationship and are responsible for each other's financial and emotional well-being" (n.d.). All subjects identified as partners were sharing a common domestic life, cohabiting during the time period of the study.

TBI (Traumatic Brain Injury). For the purpose of this study, a veteran had been clinically diagnosed as having a TBI by a medical provider directly a result of the deployment exercises related to combat to the war in Iraq. Neither the veteran nor the veteran's partner were

asked to confirm this with medical reports, but rather self-report. The characteristic TBI injuries result in varying degrees of physical, emotional, and cognitive impairments often not noted or labeled as mild given the lack of an observable head injury. The symptoms of a mild TBI are primarily frontal lobe disturbances including persistent headaches, memory problems, sleep disturbances, dizziness, irritability, anxiety, and difficulty focusing (USGAO, 2008).

PTSD (Post Traumatic Stress Disorder). For the purpose of this study, PTSD was clinically diagnosed by a health care provider using the diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV). The individual lived experiences of PTSD vary slightly, but can be grouped into three distinct categories: intrusive recollections, avoidant/numbing symptoms, and hyper-arousal symptoms. The cluster of numbing symptoms is manifested by a marked lack of interest in significant activities, emotional separation or detachment from others, and a restricted range of affect. Hyper-arousal can include exaggerated startle response, difficulty with emotional regulation leading to outbursts of anger, hyper-vigilance, insomnia, and trouble focusing and concentrating. Intrusive memory symptoms include intense physiologic and psychological responses to internal or external cues that are linked to the traumatic event, intrusive recurrent thoughts of the event, and flashbacks that mirror the actual lived experiences of the event (American Psychiatric Association, 2000). Veterans' partners self-reported all medical diagnoses, including PTSD.

Caregiver burden. A review of the caregiver burden literature reveals marked inconsistency with both the conceptualization and operationalization of the term, making it challenging to define in a manner that adds to the general body of caregiver burden knowledge. Therefore, caregiver burden was defined in a manner that was consistent with the concept as defined by many whose research is associated with the provision of care to a brain injured spouse

(Calhoun, Beckham, & Bosworth, 2002; Dekel, Solomon, & Bleich, 2005; Hayes et al., 2010; Katz, Kravetz, & Grynbaum; 2004; Monson, Taft, & Fredman, 2009). For the purpose of this study, caregiver burden refers to the caregivers' perception of the subjective and objective consequences of the emotional, financial, physical, and social demands required in the provision of care for their partners.

Study Significance for Nursing

There is little question that the comprehensive rehabilitation and recovery needs of our country's service members are critically important to the nursing profession and to the nation as a whole. The long-term health consequences for those living with and caring for a veteran with a combat acquired TBI have yet to be determined. It is known that when it comes to providing ongoing care for our nation's veterans, military spouses and partners bear the largest burden (Tanielian & Jaycox, 2008). There is a growing body of literature affirming the assertion that the partners of veterans with PTSD are impacted by the veterans' ongoing psychiatric symptoms and the partners are in need of supportive measures (Ariz, Solomon, & Dekel, 2000; Frančišković, Stevanović, Jelušić, Roganović, Klarić, & Grkovi, 2007; Manguno-Mire et al., 2007). A wide variety of studies have demonstrated that chronic caregiver burden, such as caring for a veteran partner with a TBI and PTSD, leads to a decrease in the mental and physical functioning of the caregiver (Arzi et al., 2000; Fals-Stewart & Kelley, 2005). The challenge of preparing to meet the long-term impact and costs of a combat acquired TBI for veterans will continue to need focused research and subsequent care for the veterans involved. The ongoing costs to veterans' partners are just beginning to be understood. The needs of partners are worthy of equal attention to prevent extreme distress, fractured families, financial stress, domestic violence, and a decreased quality of life for partners (Tanielian & Jaycox, 2008). It is critically important to

target this vulnerable group of individuals who are on the front lines at home, supporting our country's veterans.

The knowledge gained from this study involving partners of veterans with combat related TBIs has the potential to be useful in application to a variety of disaster events ranging from natural disasters to massive terrorist attacks. Across most cultures, in multiple settings around the globe, individuals with neurocognitive injuries find that next to themselves, their partners are the ones who bear the brunt of their injuries. Unfortunately, there are multiple instances when living through a disaster is the starting point for a life time of struggles with optimal health. One need review a few critical events of the past year to grasp the millions who have been impacted by incidents which left a physical and mental health legacy to be dealt with: the tsunami in Japan, the Arab awakening, Hurricane Irene in the United States, droughts in the Horn of Africa, bombings in Mumbai, and mass killings in Norway.

If we are to provide optimal comprehensive nursing care to veterans of OEF and OIF we must have a better understanding of the lived experiences of their partners so that appropriate supportive interventions can be designed and implemented to care for the partners of our nation's veterans.

CHAPTER 2

Literature Review

This chapter is divided into three distinct sections, beginning with an explanation of the research focus and the method used for the literature review. The second section consists of a critical review of the literature examining a broad range of aspects of partners' experiences of living with individuals experiencing post-acute neurocognitive symptoms. This second section is divided into three subsections: partners of veterans diagnosed with a traumatic brain injury (TBI), partners of veterans diagnosed with combat acquired posttraumatic stress disorder (PTSD), and partners of civilians with TBIs. Those three sections contain a synopsis of the research aimed at describing the caregiver burden related to life with a partner with neurocognitive deficits. The final section summarizes the chapter highlighting what is currently known regarding the experiences of partners of veterans with post-combat mental and cognitive conditions and identifying the gaps in the literature.

Research Focus

Blast injuries. The ongoing wars in Iraq and Afghanistan have resulted in an unprecedented number of service men and women returning home with injuries related to a blast exposure. Estimates regarding military service members with combat acquired TBIs vary depending on the source of the data, but the majority of research estimates that close to 20% or more of all soldiers return home from the wars with a TBI (Hoge et al., 2008; Tanielian & Jaycox, 2008; Terrio et al., 2009). As of August 15, 2011, the Department of Defense reports an estimate of approximately 212,470 soldiers with TBIs from combat in Iraq or Afghanistan (Defense and Veterans Brain Injury Center, 2011). The Department of Veterans Affairs and Department of Defense (2009) define a TBI as:

A traumatically induced structural injury and/or physiological disruption of brain function as a result of an external force that is indicated by new onset or worsening of at least one of the following clinical signs, immediately following the event:

- Any period of loss of or a decreased level of consciousness (LOC)
- Any loss of memory for events immediately before or after the injury (posttraumatic amnesia [PTA])
- Any alteration in mental state at the time of the injury (e.g., confusion, disorientation, slowed thinking, etc.) (Alteration of consciousness/mental state [AOC])
- Neurological deficits (e.g., weakness, balance disturbance, praxis, paresis/plegia, change in vision, other sensory alterations, aphasia) that may or may not be transient
- Intracranial lesion. (Department of Veterans Affairs and Department of Defense, 2009, p. 16)

The large majority of TBIs sustained by personnel in Operation Enduring Freedom (OEF) in Afghanistan or Operation Iraqi Freedom (OIF) are classified as mild TBIs (Brenner, Vanderploeg, & Terrio, 2009). Consensus on the time frame for resolution of the short term symptoms characteristic of a mild TBI such as headaches, irritability, and dizziness remains difficult to come by. One study suggests that a span of 30 days after the initial injury is time enough for neuropsychological recovery to occur (Brenner et al., 2009), while others suggest that three months is average (Terrio et al., 2009) and still another suggests it is reasonable to expect symptoms to dissipate within six months' time (Carlson et al., 2011). However, most agree that persistent neurocognitive symptoms such as memory problems, fatigue, impaired concentration, irritability, aggression, and sleep difficulties are indicative of either previously unidentified TBIs or the presence of an additional co-morbid condition such as PTSD or major depressive disorder

(Brenner et al., 2009; Elder & Cristian, 2009; Hoge, Goldberg, & Castro, 2009; Lew et al., 2008). As no diagnostic test currently exists to definitively determine persistent neurocognitive symptoms as being uniquely TBI related or more correctly attributed to PTSD, anxiety, or depression, teasing out a diagnosis of mild TBI is done by reviewing historical events (Brenner et al., 2009; Lew et al., 2009; Wilk et al., 2012).

Blast injuries from improvised explosive devices (IED) are the most common injuries from the wars in Iraq and Afghanistan (The Defense and Veterans Brain Injury Center, 2011). The use of “homemade” or commercially manufactured IEDs results in detonation and causes high-pressure blast waves frequently severe enough to cause a TBI with some level of neurocognitive symptoms. Additional injuries such as open wounds, traumatic amputations, auditory and visual impairment, chronic pain, musculoskeletal injuries, posttraumatic stress disorder, or burns are routinely associated with the initial blast exposure (Griffin et al., 2011; IOM, 2010; Scott, Belanger, Vanderploeg, Massengale, & Scholten, 2006). The type and severity of injuries sustained are related to the type of explosive materials used, the distance between the blast and the soldier, and the presence of physical barriers between the soldier and the blast itself. The blast injuries are divided into four groups: primary, secondary, tertiary, and quaternary. The primary blast injuries are those which are a result of the blast wave itself as it causes extreme pressure changes impacting organs with gas/fluid interfaces such as the lungs, ears, gastrointestinal tract, and the brain. Shrapnel and other objects propelled by the blast cause the secondary injuries, with the tertiary injuries being a result of the human body being blown or knocked into solid objects e.g., a vehicle or wall. Burns sustained by the intense heat of the initial blast may result in quaternary injuries (Elder & Cristian, 2009; Scott et al., 2006). The

long-term sequelae of combat related blast injuries, including TBIs, remain a virtual unknown (Eibner, 2008; Elder & Cristian, 2006; Weinberger, 2011).

TBI and PTSD. The overlap and interplay between symptoms associated with TBIs and PTSD remains a point of discussion in the literature. Multiple studies chronicle the numbers of veterans with a TBI who also have symptoms meeting the criteria for a diagnosis of PTSD. In fact, studies comprised of both active duty service members and veterans suggest that between 27% and 39% of those with apparent PTSD symptoms also have symptoms indicative of a probable mild TBI (Carlson et al., 2011; Hoge et al., 2008; IOM, 2010; Tanielian & Jaycox, 2008). Furthermore, it has been suggested that the neurocognitive deficits associated with TBIs may thwart the recovery process for those with PTSD as well as the reverse; neurocognitive effects of PTSD hinder the recovery from a TBI (Vasterling & Verfaellie, 2009). Research on the association between a combat acquired TBI and PTSD in OEF/OIF veterans and its subsequent impact on treatment is just emerging in the scientific literature. A systematic review of evidence on the subject conducted by Carlson and colleagues (2011) noted the need for consensus on measurement tools and assessment methods as well as the development of evidence based guidelines for clinical treatment directed towards the co-occurrence of PTSD and TBI.

A recent longitudinal cohort study conducted by Polusny and colleagues (2011) looked at a group of 993 U.S. National Guard soldiers deployed to Iraq. The purpose of the study was to better define and understand the longer term health outcomes for individuals with concurrent PTSD and TBIs. The researchers initially surveyed the soldiers one month prior to their return home, 15 months into their deployment in Iraq. The instrument used to determine the presence of a TBI was a condensation of the Defense and Veterans Brain Injury Center screening tool targeting altered mental status or loss of consciousness as the critical determinant of a TBI.

The researchers suggest that the 30% of those with a history of concussion or mild TBI have accompanying PTSD. Significantly, this study is one of the first, if not the first, to report that PTSD is largely responsible for long term sequelae or post concussive symptoms (PCS) of those with comorbid PTSD and TBI. PCS is a term often used in the literature to define the longer term health impairments from a TBI and is defined by this study's authors, as a constellation of physical, emotional, and cognitive symptoms that include tinnitus, headaches, irritability, diminished concentration and memory difficulties.

Additional very recent research conducted in 2011 by Wilk and colleagues (2012) at Walker Reed Army Institute of Research attempted to describe the association of self-reported post deployment health concerns with a prior concussions acquired during deployment. A sample of 1502 military personnel who saw high levels of combat was used for extensive data collection. The study participants were mailed a packet of questionnaires four to six months after they returned home from their deployment to Afghanistan or Iraq. They were asked to complete the DVBIC and DOD Brief Traumatic Brain Injury Screen and asked in detail about the possible multiple concussions. Additionally, the 15-item Patient health Questionnaire was used to determine the much a soldier continued to be troubled by a list of symptoms such as headaches, dizziness, concentration problems, irritability, memory problems, tinnitus, and balance problems. The 17-item PTSD Checklist was used to measure PTSD symptoms and major depressive disorder was assessed with the 9-question module of the Patient Health Questionnaire. Combat experiences were quantified through the use of the Combat Experience Scale, a 34-item tool which assesses exposure to combat. A number of logistic regression analyses were performed to analyze the data, specifically looking for a statistically significant relationship between post deployment symptoms and type of injury. Significant was the finding that concussions or

mild TBIs without a loss of consciousness did not have an association with any of the post deployment symptoms after the researchers controlled for depression and PTSD. Multiple TBIs with a loss of consciousness were notably associated with post deployment headaches, but the headaches were also correlated with PTSD and depression.

It was postulated that a TBI with a loss of consciousness puts a soldier at an increased risk for the development of PTSD or depression post injury. However, when all the variables were taken into account, post deployment depression and PTSD, not TBIs appear to be correlated with those at the highest risk of post deployment health concerns.

Partners as caregivers. Slightly over half of all military personnel across all branches of service are married (IOM, 2010). Therefore, one would expect the impact of the neurocognitive sequelae of a TBI has consequences for not only veterans, but for their partners as well. Several studies indicate that partners of veterans with PTSD with neurocognitive deficits from combat frequently find themselves in the role of caregiver (Dekel & Monson, 2010; Lyons & Root, 2001). Numerous studies support the assertion that spouses of veterans with PTSD are at an increased risk for emotional distress and are in need of supportive measures, but little research exists on the experience of partners living with a veteran who is living with a TBI acquired in combat (Arzi et al., 2000; Dekel et al., 2005; Dirkzwager, Bramsen, Ader, & van de Ploeg, 2005; Manguno-Mire, et al., 2007). In the latter half of 2009, Griffin and her colleagues at the Minneapolis VA Health Care System began their data collection for the federally funded “Family and Caregiver Experience Study.” The aim of the study was to identify the informal caregivers of veterans with moderate to severe TBIs and to describe their experiences of caring for their loved ones following their stay at one of five Veterans Affairs’ Polytrauma Rehabilitation Centers (Griffin et al., 2011). This study appears to be one of the first to

investigate the questions regarding caregivers of veterans with polytrauma injuries in the post-acute stages of recovery and will be discussed in more detail later in this chapter.

DoD and VA. The Department of Defense (DoD) and the Department of Veterans Affairs (VA) have initiated a series of services designed to sustain those who are supporting and caring for those who were seriously injured in the wars in Afghanistan and Iraq. In May of 2010, the Caregivers and Veterans Omnibus Health Care Services Act of 2010 was signed into law by President Obama. The law attempts to address the caregivers' needs for financial assistance, counseling, support groups, respite care, and health care coverage (United States Department of Veterans Affairs, 2011b). The VA has created a web site, <http://www.caregiver.va.gov/>, which directs users to a number of options designed for caregivers (United States Department of Veterans Affairs, 2011c). The available tools range from a VA Caregiver Support Line to local telephone numbers for the closest Caregiver Support Coordinator who is a licensed professional responsible for coordinating caregiving services in a specific geographic area, to a "Staying Strong" option. Additionally, the DoD and VA collaborated with the Defense and Veterans Brain Injury Center (2010) to create a comprehensive training curriculum for veterans' family members titled "*Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans.*" The materials lead caregivers through a series of four detailed modules explaining how the brain works, the effects of a traumatic injury on the brain and how to deal with the impact on family, how to "organize" life as a caregiver or self-care, and how to locate available services and benefits. The online curriculum includes an extensive list of online resources for further information. The VA Caregiver Services target "seriously ill and injured veterans" (VA, 2011b), those who sustained significant injuries during the war. The available services include respite care, Adult Day Health Care Centers, Skilled Home Care and Home Hospice Care. To

qualify for the Caregiver Services, one must be a caregiver of a veteran who was disabled in the line of duty after September 11, 2001. The process for applying for and receiving services appears to be fairly complex, with just one professional coordinating and implementing the program at the VA Medical Center based in a large urban area in the Southeast. The aforementioned services are designed for the caregivers of veterans who are enrolled in the VA system and “require at least six months of continuous supervision or assistance with performing basic functions of everyday life **due to a serious injury or mental disorder** (including psychological trauma or other mental disorder) **incurred or aggravated in the line of duty on or after September 11, 2001**” (United States Department of Veterans Affairs, 2011).

Community services. Many of the largest Army bases in the country are located in the Southeast. At present, veteran caregivers have access to a monthly lunch meeting for OEF/OIF veterans or “wounded warriors” and their caregivers at Fisher House on the military base. Following lunch, a guest speaker often provides a structured educational program which is followed by separate discussion groups comprised of family members in one section and the wounded warriors in the other. Additionally, a TBI support group meets once a month in the evening at the public library in the municipality directly adjacent to the military base. The church communities in the area have created a wide variety of support groups aimed at meeting the needs of the local military community. A nationally available program entitled “Combat Trauma: Bridges to Solutions” functions as the center point of a group that meets weekly at the First Baptist Church in a large city close to the base. Numerous other local churches, from a wide variety of religious traditions, offer similar programs and groups which can be easily located with an internet search.

Online social media provides a platform for non-profit organizations to reach out to veterans and partners on a 24/7 basis. Multiple groups exist on Facebook: Operation TBI Freedom, Coalition for Iraq and Afghanistan Veterans, American Veterans with Brain Injuries, and FamilyOfaVet.com - PTSD, TBI, & Life After Combat. Many of the Facebook pages have thousands of followers creating communities for both information sharing and emotional support. The Wounded Warrior Project Facebook page has over 486,500 followers with an additional 18,650 following the Wounded Warrior Family Support page (<http://www.facebook.com/WoundedWarriors?sk=wall>). A brief perusal of the Facebook walls on both sites highlights the amount of support and education activities taking place in cyberspace. Additionally there are non-governmental web sites specifically targeting caregivers of veterans with TBIs. For example, American Veterans with Brain Injuries has a live peer chat once a week and the DailyStrength's web page has a Military Families Support Group and a Brain Injury Support Group.

Many of the web sites dedicated to providing information to families of veterans are found on the OEF/OIF military and veteran web sites, but the presence of these resources comes with one noteworthy, and perhaps unexpected, burden. It takes an inordinate amount of time to "click through" each organization on the list, review the specific site's offerings, read the information, and then select and apply for those of interest. A number of the referenced links no longer function or seem to have changed their focus. On some level, it becomes a case of overwhelming choices with no guarantee that the time spent sifting through them will lead to meeting a specific need.

Method for Literature Review

In an effort to cast a wide net and gather a multiplicity of research across professional disciplines, I conducted a search of the research literature using eight different databases: Academic Search Primer, CINAHL, Google Scholar, Homeland Security Digital Library, PsycINFO, PubMed, SSED, and Web of Science. The keywords used were combat, acquired brain injury, family, wives, military, combat, traumatic stress, war, stress disorders, traumatic brain injury, TBI, veteran, spouse, caregiver, Operation Iraqi Freedom, Operation Enduring Freedom, OEF/OIF, Iraq, Afghanistan, marital relationships, support, caregiver burden, and partner burden. The proposed research question is specific to veterans who served in the wars in Iraq and Afghanistan, which encompasses the time period from October of 2001 through the present, April of 2012. However, due to the paucity of research available on partners of veterans with TBIs in the literature over the past ten years, the search was expanded to encompass the years 1990-2012.

Research on partners of veterans with combat acquired TBIs, the “signature injury” of the OEF/OIF service members is a relatively new focus of study in the scientific community and limited studies were available for review. Combat acquired PTSD has a broad spectrum of neurocognitive sequelae such as short term memory problems, irritability, difficulty controlling anger, anxiety, insomnia, and organizational deficits all of which are similar to symptoms also associated with combat acquired TBIs (Carlson et al., 2011). The impact of a veteran’s PTSD on spouses and partners has been studied extensively over the past 20 years resulting in broad availability of key research findings in the literature. Extensive research findings on the experience of being the partner of a *civilian* with a TBI were available for review. While there are notable differences in the mechanisms of injury and the trajectory of the recovery process

between the civilian and military populations, general similarities remain between the experiences of their partners. Therefore, a focused review of the literature on the experiences of partners of civilians with TBIs was included in this section. The critical review of the literature was directed towards examining the limited research related to partners' experiences of living with and caring for combat veterans with TBI and given the similarities, also those with PTSD, and civilians with TBIs.

Neurocognitive Deficits; Impact on Partners

TBIs in the military. The mental health of caregivers of veterans with moderate to severe TBIs was examined through the lens of stigma and strain in the study spearheaded by Phelan (2011) and supported by a VA Predoctoral Associated Health Rehabilitation Research Fellowship. The researchers attempted to determine frequency of discrimination and subsequent feelings of stigma experienced by veterans' caregivers. They then assessed the relationship between experiences of stigma and ensuing caregiver social isolation, depression, strain, and anxiety (Phelan et al., 2011). The study involved 70 caregivers of veterans with moderate to severe TBIs. Caregivers whose veteran partners served in combat in Iraq or Afghanistan (OEF/OIF) were not eligible to participate in the study. The majority of TBIs were as a result of a motor vehicle accident (46%) while others were due to falls (12%), blasts or explosions (8%), with the remainder of injuries either due to other causes (33%) or bullets/shrapnel (3%). All study participants were mailed a questionnaire with a number of scales and inventories tools they were to complete and return. The researchers were looking at a number of variables which required using nine different measurement instruments. They assessed stigma with the Everyday Discrimination Measure deleting five of the original ten items for space reasons. The Zarit Burden Inventory, an eight item inventory, evaluated caregiver strain. Self-esteem, depression

and anxiety and social isolation were respectively measured with the Rosenberg Self-esteem Scale, the PROMIS Depression and Anxiety short-form scales and a three-item version of the UCLA Social Loneliness Scale. Six items were selected from the Medical Outcomes Study Social Support Scale and used to appraise caregiver social support. The actual level of caregiving itself required three separate measurement categories: months spent caregiving, average hours a week caregiving and a selection from a group of 28 tasks performed which may have been done over past two weeks.

Individuals who participated in the study were a mixture of significant others (34.7%), parents (41.4%), and “others”. Many of the measurement instruments used were modified by the researchers to meet the need of mailing a questionnaire of manageable length and size which raises questions regarding the validity of the findings with the use of abbreviated instruments. The findings, while not directly transferable to the population I intend to study, do have implications for parents and significant others functioning as caregivers of veterans with moderate to severe TBIs acquired outside of the combat arena. In Phelan et al.’s findings, caregivers’ sense of stigma experienced as an additional stressor was viewed as a potentially important concept; stress fed by stigma-by-association. The researchers note that stigma is associated with diminished self-esteem which may lead to caregivers’ decreased feelings of self-worth. They also linked stigma with caregiver strain irrespective of levels of social support and time spent performing caregiving activities. The data do not specify what type of stigma the participants were responding to, leaving open many questions in regard to potential factors such as gender, race, physical attributes, engagement with systems such as the VA, or any one of potential factors influencing caregiver perceptions. The sample was small, yet 57% of caregivers returned the completed surveys. The researchers suggest that regardless of the source, a

perception of stigma impacts both the caregiver and the care recipient in terms of how both choose to cope with the additional stressor.

Effective family functioning was cited by Collins and Kennedy (2008) as an essential part of the recovery process for veterans with TBIs. The researchers listed five common stressors that family members of veterans with TBIs encounter during the rehabilitation process. These are summarized as follows: (a) unseen and unpredicted mental health effects of deployment, (b) complex course of treatment and rehabilitation, (c) loss of familiar routines and distant support systems, (d) young adult developmental stage which may include “new” marriage and young children, (e) separation from the military culture. A case study approach was used to demonstrate the complex tasks faced by families. Only one patient’s case was used by the researchers, but his case as presented did illustrate the multiple needs of veterans with TBIs. The critical need for ongoing support for families during the veteran’s rehabilitation process was suggested as a means to further “new meaning, strength, and hope” (Collins & Kennedy, 2008, p. 1002). In this study ambiguous loss theory was used to frame the traumatic loss responses of family members. The same theory provided an entry point for health care providers to strengthen family organizational patterns and communication systems. The goal, as stated by the researchers, was to assist patients and families in the construction of meaning and hope. Given the multiple professional disciplines involved in the TBI rehabilitation process and the length of time they must collaborate to provide care, the use of ambiguous loss theory as a starting point for crafting support interventions appears to be a good fit. The sample used to illustrate the case was too small to draw any generalizable conclusions, but further study has the potential to add to an understanding of ambiguous loss theory as a model for care.

Caregiving stress and burden. The concept of secondary-traumatization of wives living with war veterans diagnosed with a TBI and PTSD was examined by Israeli researchers Arzi, and colleagues (2000). Their study was unique in that it specifically targeted three groups of women; 20 married to veterans with a TBI acquired in combat, 20 married to veterans with a diagnosis of PTSD, and a control group consisting of 20 wives of veterans with no known war injuries. Of significant interest is the finding that the levels of emotional burden were highest in the group consisting of women married to veterans with a TBI. Caregiver burden and psychological distress were similar in the wives of veterans with PTSD and those women married to a veteran with a TBI. Both research groups had significantly higher levels of distress than did the control group. The Caregiver Burden Inventory (CBI), typically used for the partners of those with Alzheimer's disease, was used to measure the emotional feelings and responses of the wives to their husbands' needs. Additionally, this study used the psychological separation inventory and the symptom checklist-90R to measure the wives' perceptions of their own emotional distress and their levels of emotional and functional dependence to their husbands. When MANCOVA analyses were done to control for social-demographic variables between the control group and the study groups, the emotional distress and overall sense of burden remained significantly high in both study groups. The researchers suggest that the veterans' difficulty in day-to-day functioning is the primary cause of their wives ongoing distress and burden. The concept of wives' becoming traumatized secondary to the ongoing stress of taking care of their husbands with PTSD and TBIs finds support in this study. The need to provide clinical support and care for spouses who are caring for veterans with PTSD and TBI was strongly endorsed by the researchers.

One of the first comprehensive studies on OEF/OIF service members with combat TBIs and their caregiving family members was recently completed by Griffin and her colleagues (2011). The research study, entitled the *Family and Caregiver Experience Study* (FACES), was funded by the Department of Veteran Affairs Office of Research and Development (2011). The study's stated objective was to identify the informal caregivers of veterans with moderate to severe TBIs who had transitioned to the community from one of the five VA Polytrauma Rehabilitation Centers. An additional objective of the study was to describe the quantity and type of care being provided. The researchers had an added interest in trying to ascertain what types of resources were available to caregivers. The study was one that used a mixed methods approach, combining data obtained from mailed surveys with that of qualitative interviews. A total of 564 primary caregivers agreed to participate in the study and 338 completed the study. Two-thirds of the study participants were parents of OEF/OIF veterans with TBIs while the remaining third were spouses of the same. The participants were mailed a 35 page questionnaire to complete and return. The questionnaire was designed to obtain demographic information, describe the intensity of care needs being met, define the amount of time spent delivering care, and document any additional demands on the caregivers' time such as having young children in the home or working outside of the home.

The care recipients were primarily men, with women comprising only 5% of those receiving care. The researchers note that over half of all those providing care were also working outside the home or caring for children in the home. Almost two-thirds had limited assistance or no assistance in the provision of care to the veteran in need. A startling third reported that they did not feel there was anyone, or any system, to help them when they were in need of such. Of particular interest was the fact that the care needs of the veterans did not seem to change over a

span of time with the same intensity of needs expressed from those one year post injury to those seven years post injury. The caregivers continued to assist the veterans with “emotion management” a challenging sequelae of a TBI generally involving feelings of frustration, depressive symptoms, or anger all of which were identified as uniquely stressful.

The selection of study participants may have added a bias to the reported results in that those without significant care giving responsibilities may not have chosen to participate in the study. The recent Caregivers and Veterans Omnibus Health Services Act of 2010 had not yet been enacted when this research took place, but the study’s findings certainly document the need. Particularly salient is the uncertainty expressed around the long-term needs of veterans with combat acquired TBIs as evidenced by the consistency of the care needs over time. The researchers emphasize the necessity for continued focus and studies on this unique population of caregivers, targeting those most vulnerable to the potential negative health consequences for caregivers and care recipients.

PTSD in the military. The effects of veterans’ combat acquired mental illnesses on their partners have been extensively documented in the literature. However, researchers working with families of Vietnam Era veterans suggested that while there was abundant research available on the families of persons with mental illnesses such as depression and anxiety, there was a gap in the literature regarding the needs of partners of individuals with PTSD (Sherman et al., 2005). A few years later, intimate partners of combat veterans with PTSD were the subject of an extensive research review conducted by Monson and her colleagues (2009). Their comprehensive examination of the research suggests that the provision of support for partners of veterans with mental illnesses, including PTSD, has proven to be of great value in promoting recovery and contributing to overall family functioning (Monson, Taft, & Fredman, 2009). The lack of

documentation on what specific type of resources and relationship assistance partners need and what they ultimately find to be most useful detracts from the usefulness of the findings as presented.

In light of the gap they identified in the literature, Sherman and colleagues (2005) designed a study to investigate the needs of partners of veterans participating in a Veterans Affairs (VA) Medical Center PTSD program. The study sample was 89 women who were married to Vietnam Veterans who had a history of participation in the VA PTSD treatment program in Jackson, Mississippi. The participants completed a telephone survey that used a measurement instrument created specifically for the study. The researchers included portions of two existing assessments, the Burden Inventory and the Brief Symptom Inventory as well as questions regarding their partner's treatment needs. Additional questions were designed to elicit what kind of services would "help them to better support their loved one" (p. 1152). While unique in its stated focus on the needs of the spouses, the study was ultimately aimed at identifying potential interventions to impact veterans with PTSD. The support needs of the wives were secondary. The majority of the women were not receiving any type of ongoing individual counseling to assist with the challenges of living with veterans with PTSD. The recommendations from this study included the call for the development of new interventions designed to improve family outcomes for the veteran. There was no mention of the need for interventions specifically to improve the well-being of the partners. All of the participants were married to veterans receiving service connected disability for PTSD, yet it was unclear how long the veterans had been treated for PTSD.

While the majority of existing research on partners of veterans with PTSD is focused on various manifestations of stress or accommodation to stress, the research conducted by Dekel

and colleagues in Israel sought to examine “how women who are married to men with PTSD experience their situations” (Dekel et al., 2005, p. 25). This phenomenological study consisted of nine women, seven of whom had been married or partnered to an Israeli war veteran prior to their injury. The researchers describe the women’s experience of their partner’s PTSD as somewhat of a contagious disease in that the veteran’s family began to experience similar symptoms of anxiety and withdrawal in their lives. The theory of ambiguous loss was used to frame the personal accountings of the women’s description of what once was, but is no more in terms of their husbands as partners. The central theme of interviews was described as a tension between the wives’ desire to live a life separate from their husbands and a “fusion with their husbands and his needs” (p. 33).

Dekel and colleagues (2005) suggest the participant wives felt a level of personal responsibility to their injured husbands that is most likely specific to Israeli culture and society, where norms related to marital duty and permanence are decidedly different than they are in the United States. In Israel, the traditional family is at the center of society and divorce is considered to be outside of the central value system. Additionally, in Israel all able bodied men and women are required to serve in the military during their young adult years. This may have had a substantial impact on how an injury acquired through combat was perceived by spouses who served in the military themselves. The researchers suggested the theory of ambiguous loss as an appropriate paradigm for the partners of veterans with PTSD regardless of their cultural background or country of origin. In examining the experience of United States military families, caution must be taken in drawing too much inference from this study, or postulating how its findings might be applied in American context. Given the differences in cultural norms and

values related both to marriage and military service, it is difficult to determine if the partners of Iraq and Afghan veterans would have similar perceptions as those of Israeli partners or spouses.

Family members of military personnel who acquired a PTSD diagnosis as a result of their service in Iraq and Afghanistan have been the subject of a number of research studies. Research specifically focused on the consequences of a veteran's PTSD on their partners is emerging, but remains limited at this point in time. The measurement of relationship satisfaction as a means to demonstrate overall personal and marital distress experienced by partners of veterans with PTSD has been the focus of multiple studies (Goff, Crow, Reisbig & Hamilton, 2007; Hoge, Castro, & Eaton, 2006; Renshaw, Rodrigues, & Jones, 2008).

Research addressing the impact of a veteran's PTSD symptoms on both soldiers and their partners was conducted by Goff and colleagues (2007). They used a purposive sample of 45 couples recruited from an area around Fort Riley Army post in Kansas as they sought to understand how trauma symptoms impact relationship satisfaction. In the study sample, all of the males were soldiers with a history of recent OEF/OIF deployment and their wives were civilians. A variety of measurement instruments were used to capture individual trauma symptoms and relationship satisfaction. The instruments were as follows: The Traumatic Events Questionnaire (TEQ), Purdue Posttraumatic Stress Disorder Scale-Revised (PPTSD-R), Trauma Symptom Checklist-40 (TSC-40), and the Dyadic Adjustment Scale (DAS). The emotional numbing/avoidance features of the soldiers PTSD were seen to decrease both their level of relationship satisfaction and their wives' relationship satisfaction. Seeking to validate the assumption that severity of PTSD symptoms influences overall relationship satisfaction the researchers found that was the case in their study. Severe sexual problems, sleep issues, and dissociation were found to be the most disruptive symptoms to overall relationship satisfaction

by both partners. The soldier's lack of emotional availability was related to his significant trauma symptoms and was found to be particularly challenging to a sense of relationship satisfaction. This research study provides additional support for the growing body of work which suggests a military service member's PTSD symptoms have a significant impact on their marital relationship. Trauma from war impacts not only the soldier, but also their close interpersonal relationships, particularly their spouses.

The impact of veterans' PTSD on their primary intimate relationship finds additional support in the work of Rensaw and colleagues (2008). These researchers sought to understand the specific determinants of the partner's sense of vulnerability and well-being through the study of 49 National Guard male soldiers and their wives. The research was conducted through the use of online and hard copy questionnaires given to both the soldiers and their wives three months after the soldiers returned from a 12-month deployment to Iraq. A number of measurement tools were used to determine the soldier's trauma symptoms, his wife's perception of his symptoms, and the overall sense of marital satisfaction. Both the soldier and his wife completed the PTSD Checklist, the Center for Epidemiological Studies Depression Scale, and the Relationship Assessment Scale. The wives completed a Spouse Perception Scale which was constructed to capture the spouse's perception of their soldier's trauma symptoms and combat experiences. The soldiers completed a Combat Exposure Scale which sought to measure the level of exposure to potentially traumatic experiences while deployed.

In multiple instances, the researchers found that the wives report of their own psychological distress was correlated to their perceptions of the severity of the PTSD symptoms experienced by their soldier husbands. This finding differs from the pattern found in previous studies in part because it measured wives *perceptions* of their husband's PTSD symptoms rather

than relying on an empirical measurement of PTSD symptom severity. This study had a number of limitations including the small sample size which results in a low power to identify significant relationships between the variables as identified by the researchers. Additionally, the sample was all male National Guard soldiers who were married, limiting any generalizability to active duty service members, veterans, or couples comprised of female military service members and their partners. However, the suggestion that cognitive interpretations mediate the psychological distress and level of marital satisfaction of the National Guard couples participating in this study offers fresh perspective and a new area for further research.

In summary, researchers suggest that the partners' perception of their own psychological distress can be directly linked to the manifestation of the veterans' PTSD symptoms within the relationship. Dissatisfaction within the partner relationship has a complex constellation of core variables. The veteran's difficulty with regulating charged verbal and physical aggressions, leading to the partner's sense of personal threat, has often been identified as a particularly salient factor in the dissatisfaction (Galovski & Lyons, 2004; Monson, Taft, & Freedman, 2009).

Caregiving, distress and burden. . Throughout the literature, caregiver burden and distress is typically operationalized as depression, anxiety, sleep disturbances, emotional exhaustion, headaches, and concentration problems (Arzi et al., 2000; Collins & Kennedy, 2008). The specific instrument often used to measure the concept is the Burden Interview which is a self-report, 5-point scale tool which looks at the caregivers' sense of burden in general areas such as social life, interpersonal relations, health and finances (Beckham, Lytle, & Feldman, 1996). The conceptualization of caregiving burden takes the form of both the subjective and objective factors associated with caring for an individual with PTSD. For example, an objective factor would include the financial difficulties that may arise when caring for an individual with a

chronic illness while a subjective factor may be the caregiver's emotional response to financial strain (Calhoun, Beckham, & Bossworth, 2002). Caregiving burden may also be viewed as the degree to which the emotional, financial, social, physical aspects of the caregivers life have been negatively impacted by the provision of care to their loved one (Dekel, Solomon, & Bleich, 2005).

The consequences of Vietnam veterans' PTSD on their intimate partner relationships has also been studied through the lens of caregiver burden and distress. Noting that veterans with PTSD are known to have extreme interpersonal difficulties, Beckham and colleagues (1996) proposed they would find significant stress levels in the 58 wives of Vietnam veterans with PTSD in their prospective study. Specifically, they hypothesized the greater the veterans' PTSD symptom severity, the greater the level of burden would be experienced by his partner. They report on PTSD as a chronic, variable, fluctuating disease which places considerable care giving responsibilities upon the partner. The PTSD of the veterans was evaluated in a PTSD Clinic at a VA Medical Center with the Combat Exposure Questionnaire, the Posttraumatic Stress Disorder Scale of the Minnesota Multiphase Personality Inventory, and the Mississippi Scale for Combat Related PTSD. The veterans' partners were mailed a packet with survey requesting demographic information and four questionnaires to complete. The standardized questionnaires included the Beck Depression Inventory, the Burden Interview, the Symptom Checklist-90-Revised, and the Spielberger State and Trait Anxiety Inventory. In their discussion, the researchers suggest that couples struggling to cope with the stressors of a veteran's PTSD follow a course similar to couples trying to accommodate chronic diseases such as Alzheimer's, dementia, or schizophrenia. The study was designed to assess caregiver burden of the veteran's partner in an attempt to determine if changes in the severity of PTSD impacted the level of burden

experienced. The study concludes that the self-reported caregiver burden is directly related to the patient's level of symptom severity. The researchers did note the need for further studies on potential interventions designed to reduce caregiver burden. They suggested a number of interventions similar to those currently being used for caregivers of partners with dementia. The researchers did not utilize a control group nor seek to measure caregiver burden in a population with demographics similar to those of veterans with PTSD. This leaves the full scope of PTSD and caregiver burden difficult to accurately access.

The subjective and objective burdens of those partners caring for a Vietnam veteran with PTSD was the topic of a study conducted by Calhoun, Beckham, and Bossworth (2002). As part of their research on PTSD symptom severity, caregiver burden and the subsequent psychological adjustment of the partners was also examined. The researchers administered self-report measurement scales to 71 help-seeking male veterans and their partners who had been recruited from a PTSD Clinic at a VA Medical Center. A total of 51 veterans had been clinically diagnosed with PTSD and 20 did not carry a PTSD diagnosis. The veterans and their partners were assessed to determine the veteran's level of psychological symptoms, psychological adjustment, and the partner's sense of both objective and subjective burden. The instrument used to measure the veteran's PTSD symptom severity was the Mississippi Scale for Combat Related PTSD. The Conflict Tactics Scale was used to assess their interpersonal violence and the Cook-Medley Hostility Scale was used to measure veteran's hostility. The veterans' partners were assessed with the Burden Inventory which is designed to measure both objective and subjective sense of burden. The partners were also asked to complete SCL-90, an inventory used to measure a diversity of psychological symptoms across nine dimensions. A Global Severity Index, a summary score of all psychological distress symptoms, was calculated using the scores from the

SCL-90. The researchers found that partners of veterans with PTSD had a greater sense of care giving burden than those whose partners did not have PTSD. It is unclear why the veterans recruited from the PTSD clinic, but not diagnosed with PTSD were included in the study. There was no mention of similarities or differences in the two groups of participants. The chronic and fluctuating nature of PTSD makes the one time administration of the measurement scales difficult to generalize. Additionally, the study sample of PTSD patients had been living with their illness for greater than 25 years and over 55% of them had had a previous marriage. This makes it challenging to ascertain what possible interventions would be supportive at what point in the care giving process as there was no indication of the relationship between perceived burden, psychological adjustment, and length of time in the caregiver role. The study does support the literature which finds PTSD symptom severity is correlated with care giver burden.

A phenomenological research method was used by Ray and Vanstone (2009) to explore the impact of Canadian veteran peacekeepers PTSD on their families. This study involved a secondary analysis of data originally collected for a study focused on the experience of contemporary peacekeepers healing from trauma. The previously transcribed narratives from seven participants was reviewed and interpreted in an attempt to answer the question “What is the impact of PTSD on veterans’ family relationships and what is the impact of these relationships on healing from trauma?” (pp. 840-841). This study provided a solid background on the philosophy of Merleau-Ponty including his understanding of embodiment, perception, and time. The same philosophical concepts were applied to the interpretation which was based on an interpretive framework of Van Manen. The researchers noted the veterans’ emotional numbing and anger to be two of the most problematic aspects within the family system. Interestingly, the researchers highlighted the extent to which the barriers created by emotional withdrawal and

numbing associated with PTSD interfered with the veteran's recovery process by effectively causing the withdrawal of family support. The veterans tended to alienate close family members either through the use of inappropriate interpersonal skills or by their inability to regulate their anger, such that family members withdrew ongoing social support as part of their own self-protective process. Social support was seen to be a critical piece of the recovery process which was hampered through a circular feedback system held together by the veteran's visible PTSD symptoms within the family. The study findings are of critical importance to furthering the understanding of the relationship between a veteran with PTSD and their spouses' withdrawal of support.

A cross-sectional study conducted by Manguno-Mire and colleagues (2007) examined 89 cohabitating female partners of male veterans with PTSD. The study sample was obtained from two Veterans Affairs Medical Centers in the south, with no attempts made to limit the participants to a particular combat era, nor to PTSD symptoms of certain duration. A telephone survey instrument was used to interview the partners. The instrument consisted of selections from three published instruments; the PTSD Checklist—Military Version (PCL-M), the Brief Symptom Inventory, and the Burden Inventory. The study findings support the growing body of literature documenting the significant levels of distress and burden in the partners of veterans with combat acquired PTSD. Partners who indicated they were significantly involved in the treatment of their veteran's PTSD reported a higher level of partner burden. A possible limitation of this study is the composition of the sample, veterans who had, on average, been receiving treatment for their PTSD for over 30 years. This introduces the possibility that their partners may have been experiencing secondary traumatization making the results very difficult to generalize to any population other than those whose long-term relationship includes chronic PTSD of 30

years or more. Additionally, it is unclear how long the couples in the study had been together. Despite the limitations and lack of generalizability of the findings, this study does lend further support to the growing understanding that partners of veterans with PTSD experience high levels of distress and an emergent sense of care giver burden. This study adds to the developing body of scientific work which suggests there is a need to design interventions that target the veteran and their family so as to decrease the stress and distress of the family system. Additionally, this study views distress in partners as being linked to PTSD treatment outcomes, thereby making family interventions an imperative rather than an option.

A sample of 130 spouses participated in a study conducted by Caska and Renshaw (2011) which examined the perceived burden of spouses of OEF/OIF National Guard and Reserve service members. The researchers collected their data from a number of measurement tools: the Burden Interview, the PTSD Checklist, the Depression Anxiety Stress Scale, the General Self-Efficacy Scale, the Ways of Coping Questionnaire, and the Big Five Inventory. They used the scores obtained to measure spouses' stress and burden, self-reported spousal characteristics such as self-efficacy, and severity of veterans' PTSD symptoms. The correlation between the severity of the veterans' PTSD symptoms and the reported burden and stress experienced by the spouses was of interest to the researchers, but even more so was the correlation between spousal characteristics and perception of burden. There are number of unique aspects to this study including the study sample of National Guard and Reserve spouses as opposed to those with partners in the Army, Navy, Air Force or Marines who have a different type of social network if only by virtue of generally living in the same geographic vicinity. Additionally, attempting to link spousal characteristics, such as self-efficacy, neuroticism, and coping style with their perceptions of burden independent of their husband's PTSD symptoms introduces a moderator

most often ignored. Existing literature supports the assumption that the severity of a veteran's PTSD symptoms impacts the stress and distress of their spouse and this study found the same. The study did reveal a pattern between the coping styles of spouses and their own sense of burden, influenced by the intensity of their partners' PTSD symptoms. Spouses with avoidant coping styles had a more difficult time with their perceptions of burden related to their husbands' PTSD. The stated conclusion of this study was "although individual characteristics of spouses may be related to their perceptions of stress, service members' symptoms play a primary role" (p. 346). These findings do not significantly differ from a multiplicity of other researchers who have affirmed the same (Beckman, Lytle, & Feldman, 1996; Calhoun et al., 2002; Dekel et al., 2005).

TBIs in civilians. A review of the literature regarding the impact of an individual's TBI on their family begins in the early 1980s when neurosurgery and emergency surgery were making rapid advances such that there was a notable increase in the number of individuals who survived a head injury (Collins & Kennedy, 2008). A plethora of studies have been published since that time, a fair amount of them highlighting the challenges families face. In fact, much of the available research regarding civilians with TBIs has a focus on the adjustment of families emphasizing the difficulties many encounter. An extensive literature review on partners of civilians with TBIs will not be presented in this study as the focus for this research is on those with TBIs acquired in combat. As noted earlier, there are a number of significant differences between the two populations. However, a brief mention of studies which underscore some of the most prevalent themes will be presented.

Research indicates that all family members do not experience the impact of a TBI in a similar manner. Spouses and domestic partners experience significantly more distress following

a TBI of their partners than do parents or siblings (Anderson, Parmenter, & Mok, 2002; Verhaeghe et al., 2005). Particularly vulnerable to distress and burden are younger adults who are more likely to have small children, limited economic resources, and little social support (Verhaeghe et al., 2005). In general, researchers attribute caregiver distress and caregiver burden as a result of the various neurobehavioral symptoms caused by the TBI, while noting the contribution of financial and social difficulties often times encountered (Rivera, Elliott, Berry, & Grant, 2008; Uomoto & Williams, 2009; Verhaeghe et al., 2005).

Research on the effectiveness of interventions designed to impact the well-being of caregivers overwhelmingly focuses on the provision of education and information as a means of increasing coping abilities and decreasing the stress of caregiver (Blake, 2008; Gill et al., 2011; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007; Sinnakaruppan et al., 2005; Verhaeghe et al., 2005). A literature review of family caregivers of individuals with TBIs conducted in 2001 by Sinnakaruppan and Williams found that the primary need described by caregivers across multiple studies, was the need for information followed by a need for emotional support. The topic of caregivers, distress, and needs was addressed by a comprehensive review of the literature put forth by Boschen and her colleagues (2007). They describe a collection of literature in which the absence of empirically supported outcome measures is the rule rather than the exception. Additionally, the lack of rigor across studies inhibits the identification of specific interventions which contribute to optimal functioning and a decrease in families' perceptions of distress as they adapt to a family member with an acquired brain injury.

The psychosocial adjustment of significant others after a family member's acquired brain injury was the subject of Braine's 2011 phenomenological descriptive study. Face-to-face in-depth interviews were conducted with a small study sample of five, four of whom were wives of

individuals with brain injuries. All study participants had some level of involvement with either a brain injury organization or regional neuroscience center. The data analysis, using Giorgi and Colaizzi's methods, revealed seven common themes which arose from the interviews: (a) family functioning, (b) coping and adapting, (c) future concerns, (d) loneliness, (e) experiencing a sense of loss, (f) experienced emotions, and (g) the cognitive, emotional, and behavioral changes in a person with a brain injury (Braine, 2011, pp.158-161). An ongoing sense of uncertainty and unpredictability was shared by all of the caregivers. This was viewed as a response to the day-to-day behavioral shifts in the individual with a TBI, behavior often impulsive and irregular. Losses abounded with the term "nonfinite loss" utilized to capture the scope and magnitude of the ongoing loss process. The researcher highlighted the positive growth possibilities often attributed to the person with the TBI, but yet to appear in the literature for the caregivers. For example, caregivers' resiliency in the face of difficulties or the use of new coping skills and tools to manage the challenges presented in caring for a loved one with a TBI.

This study used an approach which sought to simply describe a family member's experiences of living with a brain injured person. The fact that the sample was quite small and obtained from those utilizing specialty health care services limits the generalizability of the findings. Additionally, limited demographic data was presented leaving readers uncertain as to what type of brain injury the family member had, the severity of the injury, and the length of time since injury. However, the study does open a window on the commonalities in the lived experiences of the study participants.

The experience of intimacy as described by both individuals with TBIs and their partners was the focus of a qualitative study completed by Gill and colleagues (2011). The researchers defined intimacy as an interpersonal sexual relationship that consisted of a commitment and

positive emotional connections. A social model was the ground from which the investigators explored intimacy as a process which involved a cycle of loss and rebuilding after a TBI. The purpose of the study was to gain a better understanding of potential support services which may be used to assist couples after a TBI.

Eleven heterosexual couples and one lesbian couple participated in the study. The purposively selected participants were recruited from a number of organizations which offer services after a TBI. Over two thirds of the couples were married and the mean time since injury was 4.78 years. All participants were interviewed using 25 primary questions related to how their intimacy had or had not been impacted by the TBI. A number of additional questions were asked of the participants designed to encourage them to describe the range of changes in their relationship including both the positives and negatives. An additional set of questions was directed towards the number and quality of social services and support services available to the couple. The interview concluded with questions asking the participants to describe potential improvements in the types and the delivery of services currently available to them.

The researchers used grounded theory approach to analyze the data, identifying two major themes: “Barriers to intimate relationships” and “Factors related to relationship strength” (p. 60). The two major themes had 23 subthemes between them with more than half of the subthemes found in the relationship strengths theme. The attention to positive attributes of the relationships provided a balance often times missing in the literature. The challenges and difficulties in the relationship tended to revolve around role strain including subsequent financial problems, emotional distress related to isolation, and the sense that the partner was a changed person. The strengths in the relationships were grounded in a sense of gratitude for life, for family ties, unselfish love, and the development of new coping skills. The researchers identified

the process of change as the most striking challenge to a couple's perception of intimacy within the relationship. Recommendations to improve the relationship centered on services available to couples throughout the recovery process and were seen as essential to the provision of quality comprehensive care.

This study illuminated a perspective that is rarely seen in the literature on partners of those with TBIs. The need to provide couple centered services to both individuals with TBIs and their partners, working with the couple as a team, should come as no surprise to those who work in the field of family and couples counseling, but does seem to be a novel approach in many other health care domains.

Research Gaps

With regard to the impact of a veteran's TBI on their partner, a gap exists in the literature regarding the longer term, post-acute injury stage. This is compounded by the reality that there is scant information of any sort available on the readjustment experiences of veterans with TBIs from the conflicts in Iraq and Afghanistan. Although, it is clear that the number of veterans with TBIs is continuing to grow. A comprehensive approach to exploring the range of psychosocial consequences related to TBI, a signature injury of OEF and OIF, necessitates the study of not only the veterans, but also their partners. One of the few articles in the literature regarding the families of OEF and OIF veterans with polytrauma and TBIs, was written by Griffin and colleagues (2009) in an attempt to understand and describe what has been done and what needs to be done. They emphasize the massive knowledge chasm around family needs related to the types of services, information, and resources necessary to assist them with coping as their wounded veteran begins the process of recovery and reintegrates back into the family and the

community. A particular void exists in knowledge related to how families adjust three years post injury.

Although there is little in the literature to illuminate the TBI experience among veteran's partners, the multitude of research regarding the impact of a veteran's PTSD on partners may hint at the stresses that could be associated with TBI, specifically high levels of emotional distress and caregiver burden. Additionally, PTSD studies have indicated that support for a veteran's partner ultimately translates into support for the veteran (Manguno-Mire, et al., 2007).

My research begins the work of filling part of the knowledge gap in the literature. When the partner's experience of living with an OEF/OIF veteran with a TBI is illuminated and described, we can construct a better understanding of the best way to move forward with providing support.

CHAPTER 3

Methods

This research was a phenomenological study intended to describe the experience of partners of veterans who suffered a traumatic brain injury (TBI) during their time as a military service member involved in the war efforts in Iraq. In this chapter I describe my research design as well as provide support for its suitability for my research question. Next, I discuss my sample and the process of obtaining it including the unexpected challenges encountered in recruitment. Following that is a discussion of the procedures used for data collection and analysis. The risks and benefits of the research are presented in a review of the ethical considerations taken to guard the rights of the study participants. This chapter ends with comments regarding the rigor and validity of the proposed study design.

Research Design

Given the current lack of information regarding the needs of veteran partners, an inductive approach was used to formulate this study design. When there is limited knowledge about a phenomenon or specific topic, use of a qualitative study design is suggested as the best fit (Brink & Woods, 1998; Creswell, 2009). The ability of a qualitative framework to assist with the creation of a lens that accurately captures the perspective of the participants within a context is advanced by Simmons (1995) in her writings on qualitative approaches to research questions in mental health nursing. She argues the need for nursing to “reaffirm its principles by pursuing research which reflects its focus on the person as a highly valued individual within a unique context” (p. 838). The use of a qualitative framework to approach my research topic, one which seeks to describe the layers of understanding embedded in an individual’s lived experience,

allowed for a more nuanced integration with other disciplines exploring the needs of this study's population (Cheek, 2002).

Furthermore, the limited research available on veterans' partners highlights the multiple factors which ultimately moderate their experience of living with a veteran with a TBI (Tanielian & Jaycox, 2008). Qualitative research offered the opportunity for the study participants to describe a more complex and detailed story of how they experience life with their partners (Creswell, 2009). The opportunity to gain a comprehensive picture of each participant's experience allowed for a better understanding of the variety of issues which come to bear on their lives. The questions were open-ended, designed to elicit data which could be analyzed for themes and patterns. Allowing the participants to reflect upon and then describe their perceptions created a better fit for this study than being driven by the construction of quantitative data which may not have applied to the participants' unique situation. It was hoped that the participants would find their participation in the research project as an opportunity to tell their stories, to be heard without the constraint of researcher expectations, and potentially to impact the way supports for them are crafted by professionals and communities who interface with them. A qualitative research approach supported that process unencumbered by pre-existing beliefs about the participants' experiences.

Social constructivist perspective. A social constructivist paradigm is the most appropriate fit for the proposed qualitative research in that it allows for the location of meaning within the context of a participant's life (Creswell, 2009). The social constructivist perspective was applied through the use of an interpretative or hermeneutical phenomenological research approach as the methodological framework for this study. The participants' shared narrative revealed the essence of their lived experience. Hermeneutical interpretation sought to reveal the

meaning incorporated into the narrative text with the understanding that there is no one true meaning (Crist & Tanner, 2003).

Phenomenological perspective. The philosophy underlying this phenomenological research was that of Merleau-Ponty. He proposed the idea that human beings develop a perspective of their lives at any given point in time based not only their prior lived experiences, but also from where they “stand,” their perception at that given moment (1945/1962). Human beings are never afforded the opportunity to be totally pure in their reflective thoughts regarding life choices as the totality of a human being’s consciousness is entangled in the essence of their constructed world forming their perceptions of the world. The focus of phenomenological study is how individuals experience their uniquely specific lives in relationship to the influences that shape their world. Phenomenology views the experience of existence as a type of co-construction in that all human beings are involved in a continual transaction which occurs between themselves and the world. It is the body “in the world” which interacts with the world. The intersection of those two points is where one’s perceptions are created and ultimately sustained (Thomas & Pollio, 2002).

The inextricable oneness of self with the social, political, and cultural constructs of the present reality serve to shape and form an individual’s daily life. Additionally, the totality of the daily life experience is influenced not only by factors of the existing time, but prior experiences as well. The philosophy of Merleau-Ponty suggests human knowledge and perception are relational, temporal, and exist in the experience of the world as opposed to set apart, singular, objective, and static (Ray & Vanstone, 2009). It is as if the past and the present continually merge and create an ever-changing image known as the individual’s constructed lifeworld (Crocker, 2009).

Perception is central to the philosophy of Merleau-Ponty who believes that all experiences are fundamentally perceptual, based on the integration of Body, Time, World, and Other People (Thomas & Pollio, 2002). He contends that people exist in the world as “lived bodies” which in turn allows them to experience or embody the world in a manner that is unique to “each body” (Sadala & Adorno, 2002). The embodiment is critical to the “catching, comprehending, and spontaneously responding to the communications of another person” (Ray & Vanstone, 2009, p. 842). For the researcher, the task is one of describing the transaction that occurs, the embodiment, and to give voice to the perceptions of the participant.

In this research, the participants’ narratives of their experience reflect the essence of their being-in-the-world with a partner who has a TBI. Heidegger (1927/1962), a precursor to Merleau-Ponty, viewed being-in-the-world as living in a time and space that is “having to do with something, producing something, attending to something and looking after it, making use of something, giving something up and letting it go, undertaking, accomplishing” (p. 83). The choices an individual makes are molded by the specifics of their lives at that point in time. Persons move through life with a freedom to choose, but only within the boundaries of their perception which is subjective. Matthews (2006) writes about Merleau-Ponty’s sense of perception and its link to embodiment stating, “The perceiver is *in* the world, but not in the same way that pure objects are: the perceiver is a subject who acts on the world as well as being acted upon by it . . . It means that we are essentially *embodied subjects*” (p. 37). Therefore, for the study participants, their perceptual experience is very much a bodily experience of orientation in the world as their access to their unique world is through the situated presence of their body.

Sample and Recruitment

Sample criteria. The participants in this study included 7 female partners of Iraq combat veterans who acquired a TBI two or more years prior to the study. They were all English-speaking adults over the age of 18 with no past or present military experience themselves. All participants had been in domestic partnership for two years or more prior to participating in the study. “Partner” refers to either the legal spouse or the co-habiting domestic partner of the veteran. The Human Rights Campaign defines a domestic partnership as “two individuals who are in a long-term committed relationship and are responsible for each other’s financial and emotional well-being” (n.d.). None of the study participants had a TBI themselves, nor did they have military experience. Only partners of those military personnel who were no longer regular active duty were in the study. Those whose partners were active duty military had direct access to specific services designed to support military families and therefore would differ significantly from non-military partners who lack the same access to system support. Additionally, those with past military experience would likely continue to hold many values central to the military culture, with its unique sense of community and customs and a defined subculture structured to provide support. There were no additional restrictions such as gender, race or sexual orientation.

One potential participant was excluded from the study as her partner, while having sustained a TBI, was still active duty military. An additional potential participant was excluded as she was the veteran with the TBI and her spouse was not willing to participate. I thanked them both for their interest, explained that they did not meet the criteria for the study, and provided them with a list of community support resources.

Recruitment. The veterans’ partners were primarily recruited from an area that extended 200 miles in every direction from a large urban area in the Southeast. Additional attempts at

recruitment were made via collegial contacts across the entire Southern region. Recruitment was an extensive process that took place over 10 weeks and used a wide variety of methods which are detailed in the narrative that follows. Initially, major downtown churches in a city directly adjacent to a military base were visited and permission was requested to post informational fliers inside the church building. Refer to Appendix D to review the informational flier. Many of the churches in the area have Sunday school classes targeted for military members and their families. A number of churches were willing to have fliers posted. During this initial time period, fliers were also posted at coffee shops, the public library, and a non-government affiliated veteran's center in the urban area surrounding a military base. After two weeks, the researcher received no inquiries regarding the study so a second set of recruitment efforts ensued which included contacting health care providers in the vicinity of the military base who were known to see veterans and their families. The Veterans Affairs Medical Clinics in the surrounding local and urban areas stated they were unable to advertise the study due to their Institutional Review Board for Protection of Human Participants in research (IRB) regulations. The local city newspapers were contacted, ads placed in the newspaper on the military base and a weekly advertising paper. All of the Veterans Service Organizations (VSO) in the regional urban area were contacted as was the surrounding county VSOs. After meeting individually with all the VSO representatives, fliers were left with the staff and at the front reception areas of each organization. The community representative at Fischer House, on base where the Wounded Warriors have a weekly meeting, was contacted and agreed to post fliers and announce the study at a weekly meetings.

Fliers were taken for distribution by three active duty military personnel who come in contact with veterans and their families; two chaplains and an Army Wounded Warrior (AW2) representative. The AW2 representative had been in the role on the military base for a year,

anticipating a transfer to another role on the same base. He himself had been deployed to Iraq and was anxious to promote the study as a means by which to assist the families of those he was responsible for in the role of AW2. To that end, he contacted his superiors, a nurse care manager at the polytrauma clinic at the Medical Center on base, and additional active duty military personnel with an interest in the subject. None of his efforts proved to be successful. Two of three chaplains who assisted with flier distribution were active duty while the other worked at a VA Medical Center. The chaplains spoke both with individuals who provided care as well as a select few veteran families who they thought may be interested in participating. Additionally, they personally contacted individuals in the VA system associated with the VA Caregiver Program, setting up lunch meetings to further network. They were unable to locate any potential participants who were willing to contact the researcher.

I contacted the Transition Patient Advocate at the VA in the large urban city whose case load consists of all OEF/OIF veterans recently transitioned from active duty. She has extensive knowledge of the services available to veterans in the community and knows key individuals in organizations serving veterans. Because she was employed by the VA and my research had not been submitted to the VA IRB she was unable to assist me with active recruitment, but provided me with numerous suggestions for where to post fliers and individuals to contact. A number of the suggested locations were on the military base and inaccessible to me, but I followed through with contacting the remaining individuals whom I had not yet reached.

Multiple efforts were made to contact the regional Brain Injury Association with the intent of obtaining information on their activities working with veterans with TBIs. After a week, I was able to speak with the Regional Coordinator for the area encompassing both the urban area and the military base. While supportive of my research and eager to assist, the staff at

the Brain Injury Association stated that their involvement with military personnel had dropped considerably over the last four years. They offered to have my flier posted on their Facebook page, but I declined such given the complications with confidentiality.

The following week, I contacted and met with the Army Wounded Warrior representative at the large urban VA Medical Center to enlist her assistance in advertising the study. Three additional contacts were made to directors of organizations in the area surrounding the military base that worked exclusively with veterans, military personnel, and their families. Fliers were left at all three settings with a personal assurance from the site directors concerning their willingness to vouch for the researcher in terms of intent and safety. At this point, four weeks into the recruitment process, the researcher had received no contacts requesting further information.

I contacted the directors of a 12 week combat recovery program focused on families and the spiritual aspects of healing from war trauma. The program was founded in the area around the regional military base and was seemingly well-connected to the community. I attempted to enlist their help in advertising my research at one of their weekly meetings. The program is free of charge, targeted to military service personnel and their families, and was in the midst of a 12 week cycle at the time of contact. Like many others, the program directors offered to assist me in any way possible as they, too, saw the value in the research I proposed. They posted the informational flier at their next session which yielded two potential participants, only one of which followed through with the interview process. Of note, the social services representative at Soldier and Family Assistance Center on the military base dealing exclusively with “warriors in transition” identified the combat recovery program as the only community resource for veterans seeking additional program activities for couples and families healing from war trauma.

The fifth week of recruitment yielded six potential participants, informed of the study by the Army Wounded Warrior representative who spoke with all of the participants prior to their initial contact with me to learn more about the study. Of note was the fact that every single participant and all but one potential participant came to the researcher via a personal endorsement by a provider known to them.

Throughout the recruitment process, many of the health care providers I contacted cautioned me about the reticence of veteran families to speak with a “stranger” they did not know, about their experiences. These warnings, voiced by people directly involved with veterans in the community, proved accurate. In the end, the success of the recruitment process relied heavily on building a network of individuals who would be willing to speak one-on-one with veterans and their partners on my behalf, vouching for my honesty, motives, and integrity. In short, the potential participants needed to know that the researcher they were reaching out to “was safe.” Finding a mechanism by which to communicate and assure my trustworthiness to desired participants proved to be the greatest obstacle to recruitment. Gatekeepers within the community who themselves assumed some risk to offer their endorsement of me and the value of this study were central to the success of this work.

When writing about the role of trust in research, O’Mathúna (2009) notes the complexity of the concept when viewed in the context of clinical research. When conducting research, trust and mistrust was primarily described as embedded in relationships. Potential study participants with a history of encountering unforeseen challenges when seeking health care for their partners in the VA system may have been less likely to contact a researcher with a history of working at the VA. Additionally, veterans with TBIs are eligible to apply for and receive a service connection in a VA disability claim related to an injury or medical condition that was directly

caused by their time in the military. The processes for making such a claim are multifaceted, time consuming and may be impacted by unexpected events such as information from a third party. Fear of disrupting the service connection process may have led to caution on the part of potential participants in terms of seeking further information.

Distrust as a barrier to the participation of minority research participants has been well documented in the literature (Yancey, Ortega, & Kumanyika, 2006). To a degree, the identified perceptions of minorities relating to mistrust of scientific investigators, academic institutions, and government agencies may be similar to the mistrust seemingly shared by the participant sample in this study. Furthermore, the stigma attached to neurocognitive deficits and mental health issues particularly in military service personnel, is real and was likely a barrier to the recruitment of individuals whose lives have been impacted by such symptoms (Phelan, et al., 2011; Tanielian & Jaycox, 2008; Weinick et al., 2011). In essence, the approach to recruitment which yielded results was similar to that described by Penrod (2003) and Yancey et al. (2006) as a process which relied heavily on community involvement. A chain of referral was initiated by the researcher contacting trusted individuals in the social networks of the sample. Working through established community based organizations and practitioners proved to be the only avenue by which participants were recruited.

Seeking additional potential participants, I met with the Director of Veterans Services at a private university in a large urban area. This institution has formulated a comprehensive set of service specifically developed for veterans who participate in the Yellow Ribbon component of the Post 9/11 GI Bill. Their Yellow Ribbon program contributes 100% of the difference between the private university's tuition and the education funds available to veterans using the Post 9/11 GI Bill and there are currently 150 veterans enrolled at the university. The Director of Veteran

Services listened with interest to my explanation of my research and took a number of fliers, setting them on a display rack in his office.

All potential study participants who responded to the fliers or ads did so with a telephone call or email to the primary investigator. The potential participants were then contacted by telephone or email to ascertain their interest in participating in the study and to assure that they meet inclusion criteria. Additional information regarding the study and proposed data collection processes was provided at the initial contact, and questions about participation were answered at that time.

Phenomenological research does not necessitate a specific number of study participants. Recommendations of appropriate sample size are suggested by various researchers including Duke (1984) who suggests inclusion of 3 to 10 participants for any one study and Thomas and Pollio (2002) who advise the use of 6 to 12 participants. The critical piece in determining the number of study participants is data saturation or redundancy in the participants' narratives. Recruitment for this study was stopped after seven interviews as data saturation had been reached. Additionally, and of equal importance, were the serious concerns of the researcher and the dissertation committee regarding the physical and emotional safety of the partners who were being recruited.

Unexpected occurrences. While I was well aware that the research involved the partners of veterans who had sustained neurocognitive injuries with the possibility of lingering symptoms, I did not anticipate the role that the veterans' ongoing mental health symptoms from concurrent PTSD would have on their partners' abilities to participate in the study. Specifically, I underestimated the potential threat to the health and well-being of the partners if their veteran husbands/partners viewed the contact with me as somehow threatening. The hypervigilance,

irritability, and angry outbursts related to the arousal symptom cluster of a veteran's PTSD have been identified as contributing to partner distress, as well as to veterans' displays of anger and violence directed at their partners (Beckham et al., 1996; Ray & Vanstone, 2009; Solomon, Dekel, & Zerach, 2008). While a number of researchers looking at military personnel estimate that a third of those with TBI also have PTSD (Hoge, 2008; Sayer, 2012; Tanielian & Jaycox, 2008; Wilk, et al., 2012), a very recent study specifically examining the co-occurrence of TBIs and psychiatric diagnoses of war veterans from Iraq and Afghanistan found that 73% of veterans with a TBI had concurrent PTSD (Taylor et al., 2012).

One potential participant's interactions with me over a three week period highlighted the need to be vigilant about participant safety as related to veterans with TBIs and ongoing PTSD sequelae. The participant, given the pseudo name of Kelly, had been informed of the research by an Army Wounded Warrior (AW2) contact. After discussing the study with the AW2 representative, with whom Kelly had a long-standing relationship, Kelly decided she would very much like to participate and requested that the AW2 representative give me her contact information so that she could get further information. I called Kelly on her cell phone and left a voice mail message with my name and telephone number indicating that she could call me if she remained interested in the study. Kelly returned my call the following day and expressed her gratitude for my focus on the partners of veterans with TBIs. The initial conversation revolved around the specifics of the research itself and an assessment of Kelly's eligibility to participate in the study. She reported that her veteran spouse acquired a TBI while in Iraq in 2007. We proceeded to set up a time and place for the interview choosing the public library as her veteran husband "Doesn't allow people to come to the house." The evening prior to the scheduled

interview, Kelly called and left a message cancelling the interview stating she had a job interview. She requested that I contact her and suggested two alternative meeting days.

Over the next two weeks we exchanged a number of voice mail messages and text messages arranging a new interview time. At one point, after not receiving a return call, I left a voice mail message stating that I would not be attempting to contact her again, but if she wanted to proceed, she was welcome to call me at her convenience. Two days later, I received a text message indicating her interest, closing with “God bless you for the work you are doing.” Immediately following that exchange, I received a text message with a “new” cell phone number with an explanation about a malfunctioning cell phone as the reason for her inability to return my prior calls. The next evening, we set up a time and place to meet for the interview. By this time we had spoken over the phone a number of times, enough for me to know a little bit about her, her children, her desires to find work outside the home, and her constraints in doing so. We ended that conversation looking forward to meeting one another after all of our contact over the previous weeks. Not five minutes later Kelly called back very emotional, stating she had to cancel our meeting as when she told her husband what she planned to do, “He got very angry and said I cannot meet you.” At this point, she was crying saying “I just do not know what to do.” After assessing for her immediate safety, I inquired about possible community contacts such as a priest, pastor, neighbor, or relative to whom she could reach out to for support. Over the next 10-15 minutes I engaged in what can best be described as crisis counseling. Drawing the conversation to a close, I suggested she contact the AW2 representative in the morning to seek additional support.

Immediately after getting off the telephone with Kelly, I attempted to reach the AW2 representative myself. It was after hours, so I sent an email with the short version of what had

transpired. While acknowledging that I did not know the family, I expressed my concerns regarding Kelly's ongoing safety and asked that the AW2 representative reach out to her and the veteran the following day. The AW2 representative sent an email very early the next morning letting me know that Kelly's veteran husband had called her, irate that his wife was planning to meet with me for a number of reasons, not all of which were based in the reality of the situation. I was told to immediately cease all contact with Kelly, something already done as the prudent choice in that situation.

The recruitment process was ultimately halted as saturation was reached at approximately the same time, but the ongoing safety concerns regarding the potential participants was becoming a factor that could not be ignored. Illuminating the issue and concern to a greater degree was the number of participants who when talking about the progress their veteran partners had made in the recovery process, reported that they would not have been able to meet with me a year ago because of their partner's emotional liability at that earlier time.

Following the last contact with Kelly, I discussed her situation and emerging concerns about participant safety with dissertation chairperson, Dr. Susan Speraw, and ultimately the full dissertation committee. At that point it was decided that all remaining scheduled participants would be further screened for safety issues, and if there was any doubt about their safety the interviews would be cancelled. As long as safety did not seem to be a concern, the remaining interviews would go forward with saturation evaluated after each interview was complete.

Therefore, following my interactions with Kelly, I asked each remaining volunteer "Does your [veteran] partner know you are planning on meeting with me?" and "Is meeting with me going to be problematic for him?" All additional participants stated their partners knew and that it would not be a problem, but their behaviors did not always endorse the same. Further

examples of the potential troublesome reactions of veterans to their partners' participation in the study are provided in the section labeled participant interviews, and give further validation of the wisdom of ending recruitment with seven participants.

Data Collection Process

Bracketing interview. Prior to conducting any interviews, I completed the process of doing my own bracketing interview. The purpose of the bracketing interview was to highlight any previously conceived ideas, biases, or attitudes that I may have had regarding the research topic (Thomas & Pollio, 2002). The process of bracketing assists researchers in becoming aware of previously unidentified bias such that they can set aside or temporarily suspend prior judgments and expectations related to the qualities of the phenomenon under study. Additionally, the bracketing interview highlights any preconceived expectations they may have regarding the participants. My bracketing interview was conducted by an experienced member of the Interdisciplinary Phenomenology Research Group at the University of Tennessee. It consisted of the researcher being asked, "When you think about your experience of working with the partners of OEF/OIF veterans with TBIs, what stands out for you?"

The completed interview was transcribed by a transcriptionist and then shared with the Interdisciplinary Phenomenology Research Group at the University of Tennessee. As the research group read the interview, they engaged in a process of identifying themes in the narrative and ultimately questioning assumptions I brought to the phenomenon of interest. The bracketing interview revealed ways in which phenomenon was already understood and perceived such that those ways of knowing could be temporarily suspended, with the intent of opening me to understanding more fully the experience of participants. In writing on the philosophical roots of phenomenology and bracketing, LeVasseur (2003) describes Merleau-Ponty's conception of

bracketing “as a kind of astonishment before the world that disrupts habitual patterns of thinking” (LeVasseur, 2005, p. 417).

Having worked at a VA medical center for seven years I was marginally aware of personal perceptions related to the care provided to veterans and their families. The efforts of the phenomenological research group at analyzing the bracketing interview resulted in the identification of a number of important themes and potential biases. The most prominent theme related to my personal frustrations with engaging and navigating the VA health care system so as to meet the needs of those it was designed to serve. At times, my frustration led to a feeling of powerlessness as I found my attempts at the provision of holistic nursing care thwarted by rules and regulations. The second visible theme was that of justice. I made multiple value statements regarding the injustices of a system designed to serve those who have served, but which often times, does not. Additionally, I had a sense that partners of veterans were often times powerless in a system which I described as a “colossal mess.”

Acknowledging that I had strong opinions related to my frustrations with what I perceived to be injustices of the VA health care system was critical for me as a researcher. I had to be cautious when interviewing participants such that I did not inadvertently probe for, and then steer the interviews to touch on those two themes. Keeping an active awareness of my proclivity towards viewing veterans and their partners through an ethical lens with subsequent value judgments placed on the system itself was vital to setting aside my biases as I began the interview process.

Participant interviews. After the participants contacted me and their eligibility for participation was confirmed, meetings were set up to move forward with the research process. The participants were interviewed by me at a day, time, and private location of their choice. I

suggested quiet rooms, glass walled small meeting rooms, in the local public library if the participant did not want to meet at their home and had no other location in mind. The interviews took place at the participants' homes, the public library, parked vehicles at a clinic and off an interstate exit, in a private room at a local church, and a private room at a religious center on a university campus.

Obtaining consent. I had had multiple emails and telephone contacts with the majority of the participants working out the specifics of meeting times and days such that actually meeting them and engaging in social conversation to establish rapport came easily. First, I introduced myself and gave the participants information about my nursing background and my interest in the study topic. At that point, I reviewed the purpose of the study, explained the informed consent form, and asked the participant if they had any questions. If there were none, I gave the written form to the participant to read and to sign. The last portion of the informed consent form was related to the participants' desire to receive a summary of the research study findings at the conclusion of the study. I explained this would likely be available in late May and asked that the participant provide me with their preferred contact information for the summary. At that point, all participants were given the \$25 Walmart gift card; an incentive also used to partially compensate them for the time spent talking with me.

The participant was verbally reminded that if during the course of the interview they told me about an immediate danger to self or others or of a potential risk of harm to a child, an elderly person, or a disabled person, I would file a report with the appropriate state agency as legally and ethically obligated.

Prior to beginning the interview and taping process, the study participants were asked to complete a short demographic questionnaire (Appendix C), which took less than five minutes.

The participants were asked to indicate their age, gender, years married, number of children in the home, and their partner's age, gender, branch of service, months since separation from military service, length of time with TBI diagnosis, and employment. The participants were told they may choose to skip questions they do not want to answer.

Interview experience. I then asked the participants if they were ready to begin and enlisted their assistance in testing the recording devices. When it was determined that they were ready and the digital recorders are working properly, the interview began. The primary question the participants were asked was, "As you think about your experiences over the past years after your partner received his (her) traumatic brain injury, what stands out to you?" I asked follow-up questions intended to either clarify the participant's narrative or to gain a richer description of the experience. Subsequent questions followed the lead of the participant's descriptions and additional questions were directly linked to what had already been said. Probe questions were only used if the descriptive process stalled (Appendix B).

Length and location. When explaining the interview process, the participants were told that the interviews would likely be 60 to 90 minutes in length, but the interview would be over whenever the participant said it was over. One interview was 32 minutes long, cut short by a cell phone call from the participant's spouse wanting to know where she was and what she was doing. The participant had been previously asked if her veteran spouse knew that she was meeting with me and she had confirmed the same. However, during the telephone conversation she told him she was at the doctor's office waiting on a lab result for their child and would be home shortly. The participant had three of her young children with her, we were meeting in her vehicle off of a rural exit on the interstate, and it simply seemed prudent to complete the interview such that she could go home if she needed to do so. I inquired about her safety, asking

if her veteran spouse would be upset if he knew she was talking with me about her experience as the partner of a veteran with a TBI. Again, she stated that it was not a problem. Her verbal exchange with her spouse on the telephone suggests that it may have been otherwise, but after receiving reassurances from her, we parted.

A second interview was 38 minutes in length with the time frame determined by the period of time the participant's veteran spouse would be with his mental health care provider at a VA clinic in an urban area. The interview was conducted in my vehicle in the parking lot of the clinic with a keen awareness of the time. The participant stated she needed to be standing outside the door of the exam room in the clinic prior to her veteran spouse completing his allotted appointment time. To accommodate her obvious concern and anxiety, I kept a very close watch on the time and we completed the interview prematurely such that she would be available to meet her veteran spouse at the appointed time.

The five other interviews were between 43 and 73 minutes in length. Young children either accompanied the participant to the meeting location or were present in the home during the time of four interviews. In all cases, the presence and needs of the partners' children were taken into account by both the researcher and the participant. During two interviews, the digital recorder was paused for short periods such that the participants could respond to the requests of their children. Yet during another interview, the pace of the interview was propelled by the participant's voiced concerns regarding the whereabouts of her veteran partner. She repeatedly mentioned that she was worried about where he was and what he was doing. Another interview was brought to a quick conclusion as the participant's veteran spouse sat down at the table where we were meeting, wanting to add his perspective and experience. Given that the IRB approval was only for interviewing partners of veterans and no prior consent was obtained to record the

conversation of the veteran, it was not possible to continue digitally recording the interview of the participant once her spouse joined us. In only one instance did the participant and the researcher meet with no notable verbalized or implicit constraints on the time period for the interview.

Response to participants. It was recognized that participants were discussing sensitive topics that had the potential to stir emotions. The participants had been told that the interview would stop and be over if and when they said so. Two study participants became upset and tearful during the interview. I handled the situation based on my extensive experience as a licensed health professional working with individuals under extreme stress. I offered to stop the interview using body language, but both of the participants indicated they wished to continue. At that point, I provided tissues and paused the conversation to allow the participants' time to regroup. I used my well-developed skill set interfacing with traumatized individuals and my professional judgment to make the decision to continue the interviews based on the wishes of the participant.

When the interview was coming to an end, either because of time constraints or the natural course of the process, the participant was asked "Is there anything else you would like to add about your experience of living with your partner over the past few years?" Two of the participants stated they have nothing left to add and the digital recorder was turned off. Four other participants spoke further about an issue that they had previously touched on during the conversation. I thanked all of the participants for their time and extended my deep appreciation for the willingness to speak with me about their experiences.

Before departing from the meeting place, I provided all study participants with a printed list of available support sources (Appendix F), making notations of ones that may be particularly

useful to them. The handouts contained an extensive list of civilian and military organizations which offered services for veterans with TBIs and their families. These organizations ranged from the Wounded Warrior Project to the Brain Injury Association of America. I added participant recommended resources to the list as time went on. I was clear that the provision of the resource services hand-out was not an endorsement of any one organization on the list, but intended to be informational in nature, giving the participants options for seeking further support. The participants were encouraged to contact me by email if they desired additional referral information. At her request, one participant was emailed the list of resources such that she could click through the embedded internet links.

Field notes. Prior to meeting with each participant, I composed brief handwritten field notes regarding the upcoming interview. The notes consisted of the number of email or phone contacts with the participant, the decision making process regarding the selection of the interview site, and the community contact who ostensibly vouched for me as “safe person”. When I got home, I immediately went to my office to complete each participant’s entry in my field notes file. The notations encompassed an overview of the process, the setting for the meeting, what the time constraints were, unexpected family members who were present for portions of the interview, the participant’s body language, and my internal responses to the interview. Most of the interviews took place at least 60 miles from my home, with three of them 180 miles away, and one only a short ten minute drive. The time spent in the car driving home allowed me to partially process my emotions related to who I had met and what I had heard during the interview. Early on in the research process, I became aware of a clear sense of admiration and respect for the participants and an equally clear feeling of frustration regarding the wars during which their veteran husbands acquired their injuries. Sharing those feelings with

former VA chaplain colleagues and former military nurse colleagues assisted me in appropriately processing prior to moving on to the next interview.

Transcription and storage. After the interviews were concluded, I went straight home to download the digital recordings in the form of MP3 files onto my password protected home computer. For the purposes of time, I transcribed the first two recordings using the exact language of the participant noting laughter, periods of silence, and voice inflections. The texts of the interviews were verbatim, save the use of pseudo names inserted for any specific names or locations. The additional recordings were compressed and sent via password protected email to a transcriptionist who had previously signed a confidentiality pledge (Appendix H). Once the transcripts were complete I reviewed them, carefully listened to the digital recordings while visually following the printed transcript to ensure accuracy in the transcription making corrections as necessary. Only after that process was complete were the digital files deleted from the original recording device. The MP3 files on my home computer were burned to a CD which was then transported to the UTK where it will be stored for approximately three years in a locked file cabinet in the office of Dr. Susan Speraw, dissertation chair. The MP3 files on the home computer were deleted at that point in time.

Data Analysis

The process of data analysis was primarily an interpretive endeavor which took place in a series of steps. First, the written transcripts were read to gain a sense of the overall essence of the narrative. Next, I continued to carefully read the narrative text identifying the units of meaning in a systematic manner, making notes in the margins of the text and ultimately entering the notes in a series of excel spread sheets to facilitate a more comprehensive visual viewing of the narrative as a whole. Following that, and as per the interpretive process outlined by Thomas and Pollio

(2002), the meaning units and emerging themes were continually related back to the narrative to ensure fidelity to the text as a whole. I looked for a convergence of the meaning units as part of the process of theme development. Throughout the data analysis process, gaining a sense of the essence of the lived experience expressed in the narrative continued to be the overarching goal.

The assistance of the members of the Interdisciplinary Phenomenology Research Group at the University of Tennessee, Knoxville (UTK) was enlisted and two of the seven transcripts were read aloud by the group members, all of whom had signed a pledge of confidentiality (Appendix G). The phenomenology group assisted with strengthening the process of analysis through the discussion of emerging themes and attention to the development of a thematic structure. The expertise of the group members was vital to the task of challenging interpretations suggested as the narrative is read (Thomas & Pollio, 2002).

Additionally, all of the transcripts, their accompanying meaning units, and emerging themes were meticulously examined by a small group of three members of the Phenomenology Research Group. The intention behind the full day dedicated to review of the transcriptions was to ensure, as much as possible, an allegiance to the essence of the participants' experience as they themselves expressed it.

Following the review of the transcripts by the Phenomenology Research Group at UTK, I returned to the individual transcripts, scrutinizing each to determine how the identified thematic structures fit with the experiences in each narrative. The field notes were reviewed for additional information which was pertinent to the formation of a more detailed description of the participants' experiences. The field notes also served as a check for any unanticipated researcher bias not yet identified in the process. The notes did not reveal any experiences which unintentionally contributed to my interpretation of the narratives.

After completing the process of identifying the thematic structure of the phenomenon under study, I returned to the participants for confirmation of the findings. Only those participants who had earlier indicated a prior willingness on their consent form participated in this phase of the research. The participants were asked if the thematic structure mirrored their experience of the phenomenon. The feedback provided by the participants was considered as part of the overall interpretation of the study findings. At the completion of the study, the participants who indicated an interest and who gave written consent on the consent form were provided with a summary of the study findings.

Ethical Considerations

This research was reviewed by the University of Tennessee Knoxville Institutional Review Board (IRB). A benefit-risk ratio was assessed for the proposed research with an anticipated outcome of a level of risks to the study participants and potential important benefits to the research community. The risks to participants included loss of confidentiality and possible emotional distress. The IRB determined that the risks to participants were sufficiently safeguarded and authorization to proceed with the study was obtained.

Loss of Confidentiality. To address the potential risk of loss of confidentiality, a number of steps were taken, described as follows. After each interview was complete, the digital files were stored on a password protected computer in my home office until they were sent by password protected email accounts to be transcribed by a professional transcriptionist who had signed a pledge of confidentiality. All identifying personal information was purged from data during the digital recording transcription process. The participant list was purged of personal identifying information with each study participant being assigned a number for future data

analysis. Completing an additional review of the transcripts, no identifying information was found to remain in the written documents themselves.

After completing the research process and embarking on the process of writing up the findings for publication, the focus remained on the experience of the partner. If the partner had revealed information regarding a specific personal experience of a veteran, it was not included in the study findings nor was it included in any report prepared for publication. All attempts were made to uphold the original study purpose as stated, to describe the experiences of the partners of veterans with TBI, not the experiences of the veterans.

Emotional distress. As noted earlier, participants were discussing sensitive topics that had the potential to stir emotions. When the study participant became upset during the interview, their situation was handled based on my extensive experience as a licensed health professional working with individuals under extreme stress. For example, I stopped the interview process for a short break, shifted the subject under discussion to a more neutral topic, or simply sat quietly after giving the participant the option to terminate the interview. The participants were reminded that they were free to refuse to answer any questions and could withdraw from the study at any time with no penalties to themselves or their veteran partners. They were reassured that their participation in the study did in no way impact any present or potential benefits their veteran partner may be receiving or entitled to in the future.

All of the study participants had relationships with community based providers whose focus was on supporting the partners of veterans and were provided with an extensive listing of additional community resources should they care to use them at a later date.

Rigor and Validity

In their lengthy discussion regarding the validity concerns in the constructivist paradigm, Guba and Lincoln (2005) note that validity is “a more irritating construct, one neither easily dismissed nor readily configured by new-paradigm practitioners” (p. 205). They go on to suggest that validity consists of an amalgamation of both method and interpretation of the data acquired in the engagement of research through a constructivist lens. The question of how the researcher interprets with rigor is central to the validity of the work which is discussed in terms of authenticity by Guba and Lincoln. They call for the use of authenticity criteria: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity as critical pieces to answer concerns about validity and rigor in social constructivist inquiry. It is worth noting the importance of authenticity in moving the research from mere findings to conclusions worthy of further investigation and investment by those bodies whose stated mission is to serve families of veterans.

In writing on the importance of validity in qualitative research, Creswell (2007) suggests researchers strengthen their findings by choosing to use a minimum of two strategies of the eight that follow: (a) extended periods of observation in the field; (b) use triangulation to review evidence from a variety of sources to solidify a perspective or theme; (c) review the ongoing research process itself with colleagues or peers; (d) continually re-evaluate the initial hypotheses in light of data or cases which provide evidence contradicting the original hypotheses; (e) be clear, direct, and honest regarding researcher bias and assumptions; (f) share interpretations and findings with participants to confirm accuracy; (g) describe findings in extensive detail; and (h) use an unbiased, uninvolved external auditor to review the entire research process and a type of inter-rater reliability.

I enhanced the validity of this study by using three of the suggested strategies. I reviewed the research process itself with colleagues and peers seeking out feedback from Dr. Susan Speraw, the UTK phenomenology research group, and nurse colleagues engaged in research themselves. I incorporated the feedback received into subsequent interviews, approaches to the text, and the process of developing a coherent strategy for analyzing the existing research. I strove to be clear, direct, and honest with regards to the potential for my researcher bias and assumptions identified in the bracketing interview process. There were two participants, who during the interview process mentioned the VA where I had previously been employed. The participants made disparaging comments about my former co-workers and how they approached patient care. I had similar sentiments regarding specific co-workers, but resisted probing further or reinforcing their perspectives. All attempts were made to describe the findings in extensive detail. The comprehensive field notes made after the interviews strengthened the credibility of the findings. The field notes consisted of the oft times complex process of actually meeting the participant for the interview, as well as my reactions and observations on each specific interview. Additionally, those participants who had indicated an interest and had given consent were contacted by me for the purpose of sharing general interpretations and findings to confirm their accuracy with the participant's experience. The use of the three strategies: reviewing the research process itself with colleagues and peers; striving to be clear, direct, and honest regarding researcher bias and assumptions; and describing the findings in extensive detail, worked together to further enhance the validity of the study.

An emphasis on rigor in a qualitative research study involves a dedication to extracting the meaning of a participant's lived experience which is most closely aligned with the participant's intent of describing their lived experience. To this end, the narrative text must be

read sentence by sentence, with the goal of understanding what the participant is revealing about their experience. Detailed descriptions of emerging themes added to the awareness of the participant's perception of their experience. Attention to rigor also required that I move from one level of abstraction to the next as the text was reviewed. It was important to check my assumptions around themes and meaning for accuracy by involving colleagues in the exploration of the themes within the text which was accomplished by the involvement of the UTK phenomenology research group. Furthermore, rigor was enhanced and research findings were strengthened through the use of a single focus intended to understand one dimension of the research question (Creswell, 2007).

Summary

The purpose of this study was to describe the lived experiences of partner of Iraq combat veterans with TBIs two or more years after the time of diagnosis. This chapter discussed the research design, the sampling and recruitment process, data collection and analysis, ethical considerations, and the rigor and validity of the study design. The next chapter will introduce the research findings.

CHAPTER 4

Research Findings

This purpose of this phenomenological study was to describe the experiences of partners of veterans who suffered a traumatic brain injury (TBI) as an active duty service member involved in the war in Iraq. This chapter presents a description of the research participants followed by tables containing demographic data of both the participants and their veteran partners. Next, will be a discussion on the thematic structure based on the themes identified from the research narratives. The chapter will conclude with the presentation of the individual themes and accompanying exemplars.

Research Participants

The sample for this study consisted of seven partners of veterans with a TBI. All met essential criteria for inclusion in the study. All were partners of Iraq veterans with a TBI acquired two years prior to the study, English speaking, over the age of 18 with no past or present military experience themselves. All study participants were married women whose husbands had been part of the war efforts in Iraq. Although all of the veterans acquired their TBIs more than two years ago, one of them had been diagnosed within the past 18 months and one veteran continues to await medical confirmation of his TBI from the Veterans Affairs Medical Center. In the case of the latter, the veteran's TBI had been acknowledged by a military medical provider while he was in the Iraqi combat theatre, but he has yet to obtain a diagnosis of TBI from the VA system of care.

The spouses of the veterans were almost exclusively unemployed with one participant working a flexible part-time job. Two of the spouses were enrolled in the VA Caregiver Support Services program which financially compensated them for their ongoing provision of care to

their veteran husbands. The sample consists of a wide range of ages and number of years of partnered life with the veteran. A summary of the partner demographics appears in Table 4.1.

Table 4.1

Participant Demographics

Participant	Age	Years partnered	Children in the home	Source of Income
1	38	20	1	Veteran works FT gets VA disability
2	53	33	0	Caregiver compensation; veteran gets VA disability
3	23	5	1	Veteran's VA disability
4	27	8	2	Veteran works FT
5	31	6	0	Caregiver compensation, employed PT; veteran gets VA disability
6	32	4	2	Veteran gets VA disability
7	37	12	7	Caregiver compensation; veteran gets VA disability

The participants' veteran husbands, while not the focus of the study, were critical to the findings as their injuries and lives greatly impacted the day-to-day experiences of their wives. At the time of the interviews, two of the veterans were employed. One was doing "odd jobs" in the military as he awaited the completion of his medical discharge process. He had been relieved of his regular duties, was taking classes at the local community college, and anticipated full time attendance to obtain an associate's degree in law enforcement. The other employed veteran had found work at the VA Medical Center approximately 55 miles from his home. One veteran was in college full-time and the remainder received service connection disability payments, were not

working, and had not been since their discharge from military service. Table 4.2 highlights the basic pertinent demographic characteristics of the veterans.

Table 4.2

Veterans' Demographics

Participant	Age	Times deployed	Year TBI acquired	Type of TBI	Comorbidity	Health care source	Employment
1	42	1	2004	Moderate	PTSD	VA	FT* work at VA
2	54	2	2007	Moderate	PTSD	VA/Private	U*
3	31	0	2008	Severe	None	VA/Private	U
4	31	3	2006, 2009	Moderate	PTSD	Military/Private	PT work/ PT Student
5	28	1	2006	Moderate	PTSD	Private	U
6	35	1	2006	Moderate	PTSD	VA	FT Student
7	43	4	2004, 2006 2008	Moderate	PTSD	VA	U

*FT-full time, U-unemployed, PT-part time

As noted in Table 4.2, all but one of the veterans had a TBI and concurrent PTSD, this comorbidity is significant when it comes to crafting appropriate interventions and care which impact the long term recovery and healing process (Sayer, 2012; Wilk et al., 2012).

Introduction to Participants and One Central Question: “Why do they stay?”

The women who agreed to meet and describe their experiences of living with their husbands who had a TBI from their time in the military, were an extraordinary group of individuals. Given their day-to-day challenges in partnered life, one may wonder, “Why do they

stay?” In fact, two of the participants talked about periods of time when they asked themselves that very question:

Wow. What have I gotten myself into here? Here I had an emotional investment and had uprooted my life trying to combine it with his and then I had all these extra responsibilities that weren't ever in my life before and it's been, it's been tough. It's been really tough and it's been really, really hard on us. But I'm not a quitter (Participant 7).

A year-and-a-half ago I was ready to just be like done. I cannot do this. I am sorry. I made these vows, but you know, at some point you've got to be like, you know, 'save yourself' (Participant 6).

The reasons for staying varied, but fundamentally they came back to their original commitment to their husbands, the men they knew prior to the TBI. In some general manner, all the participants referenced the man they knew prior to deployment, the man who kept them committed to the relationship. Being able to see glimpses of, and interact with, the husband they first fell in love with was mentioned as a very important piece in their ongoing relationships:

. . . this [TBI] is a sickness. It's not something he's meaning to do. I know the real him and as little as it is, he touches on what he used to be. And I am hoping maybe one day if I live that long, I'll see more. I'll take 50/50. Right now I'd say it's 75% bad, it's bad, but that 25% is enough to keep on doing it (Participant 2).

He has those really good days where I'm like, 'Wow! I can see him again. Oh, God, that's the guy I married' (Participant 6).

The fact that the couples married and made vows to support one another through life was clearly important to this group as a whole;

You [spouse] took that oath; good, bad, don't matter. You took the oath to love them, to take care of them; good times, bad times indifferent times. Just be there (Participant 8).

"I plan to be married to him for the rest of my life so we've got to make the best of it" (Participant 5).

As a group, these women seemed to be particularly sensitive to vulnerability in individuals, specifically in their husbands. A few of the participants came from very difficult childhood homes inclusive of abuse, early death of a parent, extreme financial stress, and being the singular survivor of a childhood family. When referencing their challenging childhood, a few participants saw it as ultimately preparing them for life with their husbands who returned from war with TBIs and PTSD:

The next year she [mother] was gone from our lives completely so I grew up with all of these things that had made me 'tougher than woodpecker lips' as it was put to me (Participant 7).

I had a very rough childhood growing up. I had to be a very strong kid, teenager. I raised my three sisters. I had to be very strong for all of that to happen and everything that happened through my childhood. I guess it made me who I was. Made me and him be together. I needed to be with him for this (Participant 3).

While these seven participants were coming from very different family backgrounds, living in hometowns and far from family, in urban settings and way out in the rural countryside, all were married to veterans with similar health issues and all had expectations around being with their husbands for the foreseeable future. Their shared approach to their husbands was put quite succinctly by the participant with the longest marriage, "Thank God I love him" (Participant 2).

Thematic Structure

After reading the interview narratives utilizing the Thomas and Pollio (2002) process for data analysis, the themes began to emerge from the text. The contextual ground for the themes was identified as that of shifting sand. Participants' lives changed from a state of relative stability during deployment, a time when their partners' emotions and behaviors were fairly predictable, to subsequent days of turmoil once they returned home. Once home, many of the participants had partners whose moods would shift from day to day, hour to hour. Very little was certain, save the sure unpredictability of what came next. Thus, participants described a process of attempting to gain footing on a landscape that seems to be in a state of constant change or flux. The five themes originating from the participant interviews are categorically:

- *"The person I married is not the person I see"*: Change and difference
- *"They just don't understand"*: Making sense of the world
- *"It transforms all of you"*: Redefinition of self
- *"I'm on an island by myself"*: Alone
- *"I won't give up on him, ever"*: Commitment and perseverance

Contextual Ground. The metaphor of shifting sand represents the contextual ground present in all of the participants' narratives. More specifically, the apt symbol of context is one of shifting sand dunes; a composite of organic matter ever changing in quality, quantity, shape, and style. The dunes themselves have visible peaks and valleys as well as those unseen, emblematically leaving one unable to prepare for what may be encountered once over a hill and facing a new depth of unknown magnitude. The pictorial representation of such is what the partners described as a day-to-day that was unpredictable, always changing, and never certain; something they "couldn't get a handle on" (Participant 2). There seemed to be no solid ground, very little with

which to grip and gain traction or footing. Additionally, as described by the partners, their lives over the past few years had been shaped and molded by elements totally out of their control. In essence, a big wind could always arise and disturb the landscape in which they were trying to live and work and breathe. The women themselves were not the determinants of their contextual ground; it was defined by the environment: their veteran husbands' TBI and PTSD symptoms.

Pictorial representation. Figure 4.1 depicts the thematic structures overlaying the contextual ground of shifting sand. Overarching, covering the landscape and reflecting back on it is the theme of "Commitment and Perseverance." This fully covers the upper most edge of the contextual ground with a sliver of space jutting out just above it. This slice, left uncovered, represents the window or possibility that "Commitment and Perseverance" will not be enough to keep the contextual themes contained within or resting upon the ground irrespective of the partners' voiced intentions at the time of the interviews. The reflection of the theme diffused over the landscape is meant to be indicative of its ability to bounce off of the other themes, to keep at least a shadow of the light on "Commitment and Perseverance." One must keep in mind that the sun rises and sets, one day after the next. Similarly, at any given time of year the earth's angle on its axis governs direct exposure to the sun. With such, a waxing and waning of the sun's reflective rays determines the lights' shadows shape and size. Thus, the pictorial representation as it appears today in the spring, may look quite different in the depths of winter. Metaphorically, there may come a time when darkness prevails such that "Commitment and Perseverance" may lose its protective glow over the landscape allowing the remaining, more challenging themes to overtake the scene overpowering the present day desires of commitment.

Fundamental to the scene is the undergirding theme of "Change and Difference." This is the base upon which everything else is built, grounding the remaining themes to the sandy

contextual ground. Keeping in mind that maintaining plant and animal life on sands dunes is at best a precarious endeavor subject to environmental and human made assaults, one can envision how “Change and Difference” has a tenuous hold on all that grows upward from its base. The themes functioning as bookends; “Making Sense of the World” and “Redefinition of Self” are intentionally placed to apply pressure on that which is in between, giving shape and form to ever matter that seeks to shift. “Alone” is place strategically in the midst of the darkness of an valley, close to “Change and Different” and heavily influenced by the shifting shadows of “Redefinition of Self” and “Making Sense of the World.” As the wives expressed their sense of being alone, they were all clear that their commitment to their husbands was sustaining and helped propel them over the large obstacles they found in their path. Feeling alone wasn’t a static state, but one with blurred edges that was open to the reflective warmth and energy of their veteran partner as well as other significant persons in their lives. To that end, “Alone” is not portrayed as a large unit, but rather one smaller in size than the others with open boundaries rather than impenetrable rigid boundaries.

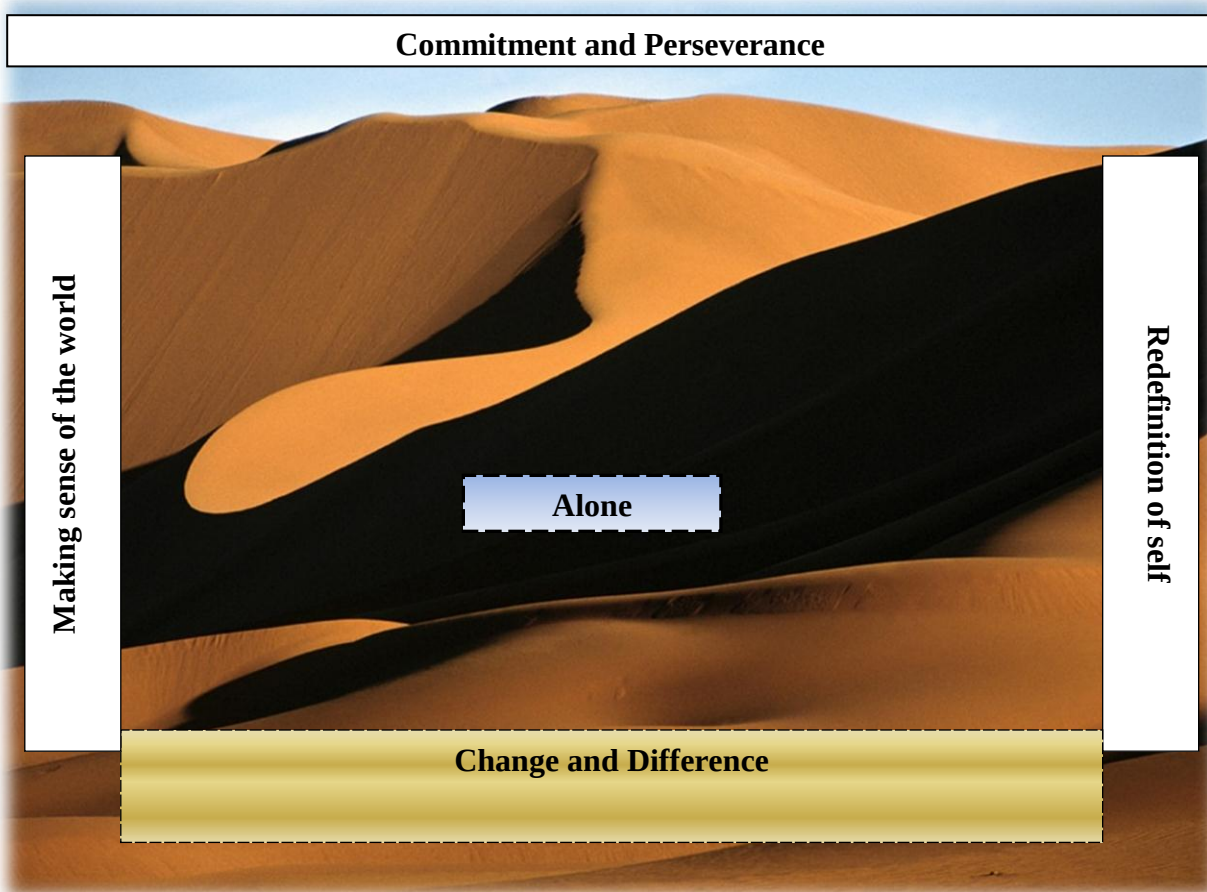


Figure 4.1 It Transforms All of You: The Lived Experience of Partners of Veterans with a Traumatic Brain Injury

Others, body, world, and time. The phenomenological philosophical approach of Merleau-Ponty is aimed at understanding the lived world of individuals. To that end, the figure-ground metaphor is used to depict the interdependence of the canvas or ground and the figures which have shape because of their relationship to the ground. Over time, the human experience resembles a kaleidoscope of sorts with the four identified existential figural themes of body, others, world, and time changing size and shape against a backdrop which can to be seen only in relationship to the shifting themes complemented with a particular figural aspect (Thompson, Locander, & Pollio, 1989).

The participants' primary figural themes were related to others; redefinition of self in response to other, set apart from others or alone, the change and difference of another weighing heavily on their perceptions of experience, making sense of the "new" world in which they found themselves as partners of veterans with TBIs. The theme of commitment and perseverance finds a closer alliance with the figural theme of time. All five themes will be discussed in light of their major existential grounds in the next chapter, but it is noteworthy that the participants' phenomenological world of "other" prevails as the dominating figural theme.

Themes and Exemplars

The themes and exemplars were primarily determined through the process outlined by Thomas and Pollio (2002). While only two of the seven participant narratives were presented at the UTK Phenomenological Research Group, all of the interviews were reviewed outside the group by two additional individuals who regularly participate in the Research Group. All of the themes identified had a number of sub-themes embedded in them. In this section, the themes, sub-themes, and exemplars will be presented.

"The person I married is not the person I see": Change and difference. If one were to simply leaf through the seven interview narratives and count the number of times the participants use the word "different," it comes to an astounding 68. Phenomenology is not a method that includes word counts, yet one cannot help but be struck by the ways and frequency with which the participants described the transformations that took in their lives as a result of their partners' TBI. Difference cut across a wide swath, if not the entirety of their lives. The spouses found themselves face-to-face with unanticipated changes in the very being of their husbands which profoundly influenced their anticipated life paths and their day-to-day lives. Additionally, they wrestled with the impact of their partners' behavior on significant relationships such as with

families and friends. All of these life alterations influenced yet another change in the partners, this one being within self; who they were and how they were in the world.

Changes in the Veteran with a TBI. The most basic and fundamental discussions of difference began with the participants' general description of their husbands. As the participants described it, even the changes were unpredictable with no set pattern; no sense of expectations that this day will be similar to the one before it or the one to follow. The women described their husbands as different with the added caveat that the "difference" was ever changing, erratic, and seemingly capricious. "Each day is different from the next" (Participant 1). When asked the first question of the interview, "What stands out to you as you think about your experience of living with your husband with a TBI?" three of the participants responded with difference and change.

It is just the dramatic change (pause). Totally (pause). Different from what, number one, what I expected our life to be and number two, just trying to get a handle on it. I can't, because it's never the same . . . It's constantly different (Participant 2).

Just how different he is. Before he deployed and before he had a TBI he was like very patient and very kind natured and when he got back he was very explosive, like his temper would go from zero to ten over stuff that was like, really minor (Participant 5).

His demeanor, as he is a totally different person than when I married him. When I married him he was easy going, nothing really upsetted him, we could talk about anything you know and there would be a resolution to it. Even if we had an argument we could resolve it. But now he has this [TBI] . . . there is no resolution to the argument, everything ticks him off (Participant1).

More specific descriptions of difference and change followed these general observations and delved deeper as wives struggled to capture in words just how the most basic qualities in the personhood or humanity of the veteran had shifted post TBI.

He wasn't, he wasn't there, him, himself. He was not there. I had no idea who this person was, at all. And it was just, I mean I felt like he was dying . . . So, it was very, very rough for me . . . They're [spouse] very mean. Kinda like a person with Alzheimer's, very mean (Participant 3).

At first, it was frustrating because it's like, that's not the man, that's not the person I knew. That's not the person I married (Participant 7).

His moods [change]. His, just his thinking capabilities, his trying to reason, trying to focus on things. Trying to just have a conversation is almost impossible . . . It's nerve wracking which is frustrating. It's just really hard . . . especially with somebody that you've been with for 33 years. He's totally different. It's like sometimes he's like almost normal, like he used to be (Participant 2).

Participant 6 summed it up for herself and others in saying:

There are a lot of wives out there who I think are like me when, you know, [their husband] gets home and it's like (gasp) 'Oh my God! Who is this person? And what are we going to do?' I had no idea. Not a clue.

One particularly disturbing aspect of the "new person" the participants saw was that the changes were fluid and unpredictable with no set pattern. A number of the participants learned from direct experience that they could never trust or expect that any given day would be similar to the one before it or the one to follow. The women also added the caveat that the "difference"

was ever variable, erratic, and seemingly capricious. For example, Participant Six concludes the interview focused on the unpredictability of her days:

Every day is new. I wake up going, ‘Okay. What’s going to happen today?’ Every day . . . You can’t plan anything. You can’t say, ‘In 30 years this is what we are going to be doing.’ No. You are sitting here thinking, ‘Okay, in 30 minutes *hopefully* this is going to happen . . . You will have a day of positive and then you will have two days of negative. It’s, it’s um, every day is surprising.

One participant described alternations in her husband’s behaviors as dramatic, affecting not only his “humanity” but the totality of the lives in very unpredictable ways:

I can’t [predict the day] because it is never the same. It is never the same. It’s not like, ‘Okay, you know he is going to be like this and this is the way he is going to be, because he is ever changing. It could be hour to hour, day to day, week to week. It’s constantly different. I have to be aware all of the time . . . I have to try to think for him to anticipate what might come his way to trigger him off. I have to try to remember to do the things the way he wants them done (Participant 2).

All of the participants made note of some sort of post-war change in their husbands which impacted their relationships as couples. Many identified the source of their spouses’ “difference” as directly related to the ongoing symptoms of a TBI and PTSD as played out in their shared lives. In that respect, they were absolutely correct as the neurocognitive sequelae of TBIs and PTSD include a wide array of symptoms which are particularly salient in intimate relationships: identification and expression of emotions, impulse control notable around the expression of anger, ability to recognize the emotional needs of others, and ability to socialize in a general sort of way.

[Talking about changes] . . . It's always stuff that I'm like, he's gonna get it. Like the very common things and then whenever the thought process that he goes through or someone says something and he doesn't understand why that would bother someone . . . He doesn't process other people's emotions sometimes or why they react the way they do to different things. It's just that everything is very cut and dry on how he reacts to things. Either it really bothers him or he just numbs it . . . For a long time I felt like he didn't understand like why some things would upset me. We would have an argument about something and I would be upset and he was very cold about it. Kind of like, "I don't even know, why this is bothering you? Why are you so upset about it?" And, there was no, there was no way to talk to him and make him understand why it affected you [the spouse] the way that it did. It's like the person you're supposed to be able to talk to and share your feelings with. . . it's hard to share those feelings with them because they don't make sense to them and so it's hard for him to be understanding of why I'm upset about something or why, you know, why I don't want to do this or why I don't want to do that or why I make some decisions that I make. It doesn't make any sense to him (Participant 4).

Some of the women were particularly eloquent when discussing their sadness at losing the one-to-one relationship they once knew and which they had hoped to enjoy again once their husbands returned home from their deployments:

It's different. It's different. Husband and wife should be helpmates to each other and we're not. It's I feel like I am doing it by myself because I have to be the responsible one, alright? Every once and awhile he will do things, like I said, that would make sense and then that kind of makes me think "OK." You know. "Maybe it's going to be a good time.

Maybe he's going to be normal today." And it may be for a little while, but it will change and he's . . . useless? (Participant 2).

I never thought in a hundred years I would have stayed in a relationship like this, especially considering the emotional roller coaster all the time and having to step into position to where I thought I would be, you know, the happy wife, have the nice head-strong husband, you know, who would bring home the bacon and be all the things that you see that you would expect from the perfect marriage and I don't have that, by no means (Participant 6).

A particularly expressive description of change was provided by one woman when she was asked what it was that she would most like for her friends and family to understand.

"Just how different they [veterans with TBI] are. You know, well, traumatic brain injury, not technically him. We all know him from before, but now you have to learn a whole new person" (Participant 3).

Yet another participant was very specific saying,

"Before he deployed and before he had the TBI he was very patient and very kind-natured. When he got back he was very explosive, like his temper would go from zero to ten over stuff that was really minor" (Participant 5).

Change in self. The participants saw so many aspects of their husbands' humanity altered after the acquisition of a TBI and PTSD. This resulted in profound changes in how the women interacted with and responded to their spouses. More importantly, it resulted in how they perceived fundamental changes within themselves.

I was trying to live a different life at work versus home, and like at work I was cheery and bubbly and happy, and I could laugh, and at home I had to be real quiet, and I had to

be careful what I said and ... [at home] it was trying to be a completely different person than my personality was ... (Participant 5).

A few of the spouses articulated how they had worked to be more aware of their reactions to their husbands and learned to alter the same:

It was like, 'OK, there's something more going on. You're [the veteran] not just an angry person. At that time, it was crazy. It was like on eggshells, especially for me. I just felt like I had to be so careful with what I said, and how I said it, because I was afraid I was going to just set him off (Participant 4).

My whole life is changed ... everything that I had to do, learned, lived through, was, has got to be different. I had to change (Participant 2).

Not only was their "whole life" changed, but the translation into smaller units of weeks and days were equally impacted:

Every day is new. I wake going, 'Okay. What's going to happen today?' Every day ...

'Okay, what's going to happen today? Is this going to happen? Is that ...' It never stops.

It is every day (Participant 6).

After stating that her day-to-day with her veteran husband pre and post-deployment was a "huge contrast, difference, night and day," Participant Five goes on to describe the change that took root in her, in response to him:

It's kind of funny. I don't really talk to people about this, but it used to be the biggest part of my day was like, 'What am I going to do? I'm going to go to work and then am I going to go work out? Am I going to go eat with a friend?' And now the biggest part of my day is, 'Okay. How do I handle this situation?' It's so much responsibility.

Similarly, Participant Six spoke of how the unpredictability and change simply never stop and end up driving the design of her days:

Every day is a new mission in and of itself for the spouse. The veteran knows that their purpose in life is to get up. . . . The spouse of that veteran gets up every morning and says, ‘Okay. Is today going to be a good day or a bad day? Is somebody going to cross [the veteran’s] path?’ . . . You are exhausted already just with what has to be done by that time [before lunch] and you try to make sure things happen and anything that you as the spouse tried to necessarily plan for yourself is never in concrete. Never. You might say, ‘Yes, I’m going to get my nails done at 4:00.’ And sometime between noon and 3:00 your husband could have a breakdown or somebody could piss him off by making the wrong comment. Nothing is in concrete. Nothing whatsoever . . . You damned near don’t breathe every day. Sleeping is minimal. I don’t go to sleep until I at least hear him snoring, which is about two hours after we go to bed . . . you still get up an hour or two before your spouse does and then you are right back to, ‘Okay, what’s going to happen today?’ Is this going to happen? Is that?’ It never stops. It’s every day.

The quality and quantity of change and difference as revealed in the lives of the partners is nothing short of profound with an overwhelming impact on every aspect of every piece of life as experienced by those in this sample. It is not a stretch to compare the alterations in the veteran and in the spouse to the blast waves that originally caused the veterans’ TBIs; a force which transforms the totality of all in its path, permeating the environment with unseen, unpredictable, and unknown long term consequences.

***“They just don’t understand”*: Making sense of the world.** Visible on a path parallel with the first theme of change and difference were the partners’ attempts to understand or make

sense of their “new” world. First and foremost there was a need to make sense of their husbands’ new way of being in the world. Another closely aligned aspect of “making sense” involved healthcare and health practitioners, since learning about TBI, and their husbands’ cases in particular, almost always involved, at least to some extent, the medical providers involved. After their prior enlisted experience of working with the straightforward military health care system, participants and their veteran partners were challenged by the processes for engaging the bewildering bureaucratic maze of the veteran health care system. Finally, participants were continually engaged in attempts to assist family, friends, and the general public in coming to an understanding of what a TBI is and what it means to live day-to-day with someone with at TBI.

Understanding their spouses’ ways of being in the world. The first priority, coming to an understanding and acceptance of their husbands’ new ways of being in the world, was often shocking, demoralizing, and confusing, since the person they knew and sent off to war came home with unfamiliar challenges and ways of relating.

He’s so mixed up. It doesn’t make any sense. It makes no sense the way he thinks. None. . . . And I’m not saying that it’s all him, but it’s me trying to understand what it is and I just can’t. I can’t figure it out. I can’t because it’s never the same. It’s hard to know (Participant 2).

It’s taken about the course of four years [for me] to realize that his anger has nothing to do, even if he targets it at me, it has nothing to do with me. [much of the time] he would just get mad and he had expected people close to him to just read his mind (Participant 5).

The challenges in trying to learn the new constructs of the partnership post-deployment and post-injury were initially a struggle for a number of the wives. Often times the task of a

“new understanding” was untaken in part to determine whether or not they wanted to remain in a partnership with this “new” person and then figure out just how they were going to do so.

And I had to learn who the new him was and if I wanted to stay married to him because he is a totally new person. And he had to understand to give me time to get to know this new person. And us work together after we both understood (Participant 3).

I feel like that I should, that I have to, not should, I have to be there for him whenever he needs me . . . When he was first diagnosed I wasn't there for him, so therefore he did a whole lot of crazy things. You know, that's when I learned from my mistake of not being there for him . . . He did a whole lot of stupid things that I don't think he would have did if I was there. He blew through a whole lot of money. . . As far as I feel as if I was there, he really wouldn't have done that. He said the reason that he done that is because he felt like I wasn't there for him. So that is why I feel like I *have* to be there for him (Participant 1).

“Making Sense of the World” was based heavily on the veteran partners who were in the participants' world “disrupting everything” (Participant 1). This resulted in statements such as, “It's very, very hard to get people to understand that it's very, very different . . . and I didn't know. I didn't know what to do. I was frantic” (Participant 3).

The majority of the women mentioned their veteran partner's memory problems as having a significant effect on their day-to-day lives. By and large, the spouses strove to understand the veterans' short term memory loss in the context of unanticipated aspects of the lingering TBI symptoms. When asked to say a little more about how she deals with her husband's memory problems, Participant One described how she now works with her partner as

she strives to understand the world from his point of view, adapting her approach to his needs after an initial period of conflict and struggle:

He'll deny it [yelling at their daughter]. He'll say, 'No I didn't do that!' I'm like 'Yes you just did that.' So he'll just deny the whole thing. I don't know if it is because he thinks that he actually didn't do it because he has problems with his memory. . . Everything now has to be written down or either I will text him. Things that he needs to remember like his doctor's appointments. I have an iPhone so I put a lot of his appointments in there so when it comes close to his appointment then I will text him or call him or email him (Participant 1).

Almost to a person, the participants were anxious and eager to learn more about their husbands' medical conditions. They expressed a real need to understand the neurocognitive symptoms related to TBIs and PTSD such that they could begin to appreciate the translation of the same as it unfolded in their lives:

I would just pick up a book or go on the Internet and start reading. 'What is going on here?' And so basically it [gaining understanding] was just me doing a lot of research and reading about 'What could this be?'. . . I had to educate myself. And it took a lot of time and patience to learn (Participant 5).

When retelling the time her husband was discharged from the hospital, Participant Seven highlights her quandary with not knowing or understanding what comes next:

Nobody gave me a handbook and said 'This is your soldier now. Good luck with him.' That's basically what I got, 'Here you go. He's back. He's done. He's injured. Here you go. Well, what do you want me to do? I am not a nurse or a hospital or a doctor and I have all these kids on the side. You know, what do I do?' Well, it's kind of like kids; trial

and error. You don't get a book with them either. So, that's really what I did . . . trial and error. That's the biggest thing, that's the worst thing, because you're just the blind leading the blind (Participant 7).

Family and friends. The work it took to get family and friends to obtain some grasp of the participants' world was often times frustrating and shameful for them. One participant used the illustration of their veteran spouse putting milk away in the cabinet rather than the refrigerator as an example of what she encountered when trying to explain her veteran spouse's behavior to others:

His family doesn't really understand at all. They don't want to. And my family doesn't understand. They just really don't understand what it's like having to deal with it and a lot of people don't. If you explain some of the things we have to go through on a daily basis; like he'll put the hot dogs in the pantry instead of the refrigerator, there goes a whole thing of hot dogs. Putting the milk in the pantry or in the cabinet, there goes a whole gallon of milk. Things like that where my neighbors will say, 'Oh, well, we do that sometimes' and it is just not like that (Participant 3).

I remember those first couple of years, like I barely even talked to my mom because I was like, 'I don't know what she is going to say or what she is going to think when I say,' you know, 'x, y, or z.' You know, she is going to think my husband is a horrible person or she is going to be like, 'Why is she still married to him?' But I felt really ashamed. Like I know it sounds ridiculous, but I was like so ashamed. I'm like, 'Oh, gosh. I've got to put this in the closet and nobody can know about this' (Participant 5).

Participant Five continued with another very similar story, corroborating the comments of Participant Three (above):

When we found out that he had a TBI there were a lot of things about. . . the girls I worked with, I would try to share with them what was going on and they would be ‘Oh, my husband does that, maybe my husband has a TBI.’ It was like, ‘Okay, I can’t talk to you all.’ It’s not as cut and dry as that.

Educating the broader world. Not only did the participants speak of their personal quests as they tried to make sense of how the post-TBI symptoms were expressed in the behavior and cognition of their husbands, they also identified the need for TBI education for the world outside their nuclear family:

When they [doctors] first mentioned it, of course I googled it and tried to figure out as much as I could about it. . . The more I researched it, the more you start to find out that even little concussions can cause so many problems. . . It’s a real problem, you know.

There are so many things that people don’t realize that a TBI affects (Participant 4).

Participant Three relayed a story highlighting her attempts to help her manager at work understand the need for a flexible schedule, introducing the topic by saying, “It’s very rough to get people to understand how it is.” She described a particular day when she was concerned about her husband and wanted to run home to check on their four year old son, but was unable to do so. She went on:

It’s very difficult to get people to understand what it is like having to live like that every day. . . Not a lot of people understand and I don’t think most of the world will any day, and I hope to accomplish that one day. To let people know what it’s like for us. They do,

really do need to kind of understand a little better. I mean a lot of people need to understand it (Participant 3).

In that same vein, Participant Five spoke extensively about the need for society as a whole to learn more about soldiers returning with neurocognitive injuries:

Society is the people in the next ten [years] . . . who are going to encounter these [veterans]. And I actually saw, the other day there was a guy at McDonald's and he freaked out. They had uh, we stopped to get sweet teas and we were standing there and the lady was like, I don't know what it was, 'We don't have...' something and he is, I mean, just blew up and people were like, 'Oh my gosh. What is wrong with him?' And I was like, 'He has PTSD.' And you know, like I saw his wife running after him and he was (yelling) in the parking lot. And my husband was like, 'Oh my gosh. Was that me?' And I'm like, 'Yeah, that was you.' But, you know, they are going to be a burden on society and I think it is really great that they are trying to help Vets get jobs and believe me I think it is a super, super good thing, but when people see them freak out like that it's because there's not that middle, you know, thing, it's 'Here's your life' . . . I don't know if that's [charity work] going to be enough for the mass amount of people who are going to come home with PTSD and TBI and the wives and the families and the towns that they live in. We need to educate them about what war is and what it does to you and, you know, I'm not saying that it is acceptable for them to act that way, but if there is nowhere for them to go in the middle, to figure out, you know, this isn't normal or this isn't how society functions, then we are not helping them. We are just, we are kind of, 'Oh. That's just them. Oh, it's just them.' And it's going to affect everybody. We've got to do something.

The participants' need to gain personal understanding of their spouses and have others understand how a veteran's TBI affects the lives of those around him seemed to be an essential part of the healing and recovery process. To be heard and understood is a simple human longing in the best of times and all the more so when times are difficult. It comes as no surprise that the women in this study expressed their need to make sense of the lives they were living.

***“It transforms all of you”:* Redefinition of self and others.** The pressing need to learn more, understand better, and somehow create order out of the “new” life, of living with a veteran with a TBI, acted as the prelude for the next theme; redefinition of self. As a broad theme, redefinition of “all” of a person has sub-themes: self and roles, career, and military to civilian transition.

Self and roles. Every single participant gave moving and sometimes painful, expression to how they experienced the role changes in their partnership following their spouses' TBI, beginning with the lament of the first participant: “Previous, I had a partner in everything and now, I don't feel like I have a partner. I feel like, I'm wearing all the hats so to say.” Throughout her interview Participant Two brought up how her veteran partner's very significant injuries have impacted how she sees herself as woman and wife:

I have to try to think for me, to try to keep things going. I have to try to think for him to anticipate what might come his way to trigger him off. I have to try to remember to do the things the way that he wants them done. It's like I have no independence to try to just normally, just, being a woman . . . because you can't have a conversation and tell him, like husband and wife. ‘You know, well tomorrow I've got to get up and I've got to do this, this and this.’ Husband and wife should be helpmates to each other and we're not . . .

She went on to follow that same thread all the way to its' core as she clarified what the shift from having a life partner to being a caregiver meant to her:

I want to live. I want to do things, I want to be able to, I feel like time's running out. It's like I have to stop living. Can you imagine just trying to live in a house or just wanting to discuss something with somebody, what we need to do, or how we should go about doing it? It's like when I do try to discuss it with him I go through the motions of telling him stuff. It's like I just get tired of talking to him. It's awful.

The danger in the abrupt role change from partner to caregiver held great risks for a few of the women. The potential to come unmoored from the familiar rhythm and rhyme of daily life as an adult couple and move to a life strictly dictated by caretaking was smothering to one woman;

I'm at the point to where I can't deal with things by myself and keep being the person that I think I am. I'm losing myself slowly . . . I've more or less having to take care of him to keep him on a path and put my dreams and aspirations to the side (Participant 6).

All of the participants were accustomed to assuming new roles, taking on additional tasks when their husbands deployed. What they did not anticipate was maintaining post-deployment their already expanded list of things to do to keep the family afloat:

Usually, you can both help out with a lot of things [normal household]. In our family, I do most of the things. He can take out the trash, he loads the dishwasher . . . but your main things: paying the bills, making sure everything is paid on time, making sure you have groceries in the house. . . I do all the driving myself. I don't like driving at all (Participant 3).

Participant Four simply put it thus, “I’ve taken on a much greater role in taking care of the family from what he was able to do when we first got married.”

Many of the partners found themselves learning new skills, taking on roles somewhat foreign to them. Coaching and refereeing were new to many of them. One acquired the ability to assist her veteran partner at his work place through dialogue about his difficulties:

I mean every job he has had, there have been something [sic] there that has happened that has really got next to him. . . So, I just listen and then I’ll say ‘Do you really think that should have bothered you?’ or ‘Do you think they intentionally did that?’ And he will sit and think about it for a minute . . . As far as being a referee, it’s not like I am a referee there physically doing it, but I may talk to him about it. There have been some incidents where he have called me [sic] from work and say ‘This is happened.’ And I am like, ‘Okay, do you really think you should be upset about that? Why not just blow it off and move on to the next one?’ I guess by me not feeling what he feels, it is kinda hard to umm . . . explain different things (Participant 1).

Yet another participant talked in a serial fashion as she described the added responsibilities she has taken on including assuring that her husband, who has returned to school, completes his work:

I’m the caretaker of everything. I do all the bills. I make sure he does his homework. I make sure he studies. I clean the house, cook dinner, do the laundry, make sure our car, our vehicles are maintained. I take it to the shop to get the oil changed. I take it to go have the tires rotated. Everything. I do everything and that is above and beyond frustrating because I have, I feel overwhelmed all the time and I get behind in my stuff

that I need to do . . . because I'm worried about making sure everything else is done (Participant 6).

The usual everyday household activities are challenging for one participant's veteran partner, so attempting to assist him with relearning the process, she details a household chore such that he can participate:

I put together the list of three things every day [what he needs to do]. We try to make him a list of three things he can go from start to finish on. Sometimes, it's unload the dishwasher and I write steps like, 'Step one-open the dishwasher.' It sounds really sad, but when he gets so overwhelmed, if he looks at three things and says, 'I have to put dishes in the dish washer and I have to unload the dishwasher and I have to clean the countertops.' To him that's so overwhelming; 'Oh, my gosh, I can't do this.' I write down what the three tasks are and then I write down how they should be done. It's not, it's not hard stuff. I'm not asking him to sew patches or make a quilt. It's everyday stuff that he is just relearning to do. Like to do laundry you have to sort it, you have to make sure the water temperature is on hot or cold. Turn the dial . . . (Participant 5).

This same participant has clearly taken on the role of teacher. She "sets out reminders like on the door there are flashcards; wallet, keys, phone." She does all of this and more, stating "I am basically his caregiver." Going on she said, "It's really hard because he requires pretty much 24 hours a day, 7 days a week care." In reflecting on how that has been for her she noted:

It is almost like having quintuplets or something, like, it is so hard to care for two people when one of them has a disability because not only do you have to be a caregiver, also a friend, and a partner (Participant 5).

Redefining roles often includes adding the role of caretaker or caregiver and altering the adult partnership from one of equals to one of parent and child. This was described collectively as being the veterans': support, parent, caregiver, advocate, backbone, friend, protector, buffer and partner.

I've had to step into a role of being wife/mother to my husband. . . It is almost like we are married, but we are not. We are like mother and child. We are caregiver and patient instead of being a couple like we are supposed to be . . . Like I said, we are like mother and child or caretaker and patient. Very rare and seldom are we in the same circle (Participant 6).

A similar redefinition was mentioned by others. "I'm his protector. I'm his parent pretty much. I mean, don't mess with me, with my child, kind of instinct is what I have now" (Participant 3). Participant Seven spoke of being "a buffer" between her husband and the world. "We actually had to go to a thing, a class to learn how to buffer, be the go-between." When asked to clarify what she has "taken on" this same participant talked about her husband in terms of being his parent:

It's kinda like, in all honesty, not being cruel or anything, it is kinda like raising a kid . . . I just have another kid. He's my biggest kid. He's my biggest handful. He talks back. He gets angry. And in the long run, he does it, but he's like any other teenager. . . I'm the one that keeps him kicked in the butt to get up and move. I'm his ambition, his goals and his pusher. Like I said, he's my biggest kid (Participant 7).

Being the caregiver meant accompanying the veteran spouse to medical appointments. In fact, one veteran was asked to bring his wife to his appointments. She was eager to participate in her husband's care and according to the participant, the doctors told her husband:

You bring her to every appointment. We want her in there with us. We want to talk because she's your voice and everything . . . His wife is the caregiver and she's basically his memory . . . I guess I didn't realize how much I did for him (Participant 4).

The vast majority of women found the new caregiving role to be a continual source of stress and low level anxiety, a daily worry that never dissipates of its own accord.

Right now I'm wondering what he's doing . . . I'm worrying. I'm right now sitting here thinking, 'Okay. Did he go home? Did he, is he over here? Is he, what's he doing? Is he working on homework?' . . . It's just what's going through my mind right now, sitting here. I worry twenty-four/seven most of the time about what he is doing, if he's okay (Participant 6).

One participant described an incident where her veteran spouse began to withdraw from family and friends, a situation she was ill-equipped to manage.

I didn't know. I didn't know what to do. I was frantic. I had a nervous breakdown at the age of 21, 22. Yes. I was not used to it . . . [I worry now] Constantly. Daily. I go out and I constantly worry about what's going on here. I do a great job when I am out, do a great job, but it's constantly worrying about home. Constantly worrying if he's [husband] asleep and if my little one [4 year old] is outside [unsupervised] (Participant 3).

The partners in this study were caring for themselves, for their veteran spouses, their families and had also assumed a number of new roles, new ways of engaging with the world, which across the board, now included worrying in some form or fashion.

Career shifts. For many of the study participants, this redefinition of roles was not undertaken lightly, nor was it easy. Three of the seven had quit their jobs to be full time

caregivers for their husbands. Giving up school and work, moving from the work world to the home front was a challenge:

Yeah. I'd like to go back to school and get a master's degree in something and be like in the corporate world again without worrying about 'What is he doing while I'm not home?' or 'How is this going to affect him? If I take a job in California is this going to uproot his life? If I choose this career and I'm not 100% accessible to him, how will that affect him?' I want to be to a point where he's, I want normalcy someday where he goes back to work, I go to work. We kiss each other in the morning and see each other at five that night. I don't know that that will ever happen (Participant 5).

There appeared to be a multitude of interwoven positive and negative effects to the decision to stay home as caregiver and terminate work outside the home:

I think for my sanity, I had to quit my job because I felt like I had the weight of the world on my shoulders. I had a 40 hour a week job and then I had the kids, where I felt like I was for and then taking care of him and I had to care of the house. I was like, 'Okay, I've got to alleviate something because I am going crazy' You know, it's turned out where [quitting my job] was probably the best thing we could've done because I am a lot less stressed. I am able to be at his appointments. . . It kind of made me upset with myself that I didn't do it before, but I guess it was like I was clinging onto something that was mine, but it's not, it's not worth it and I am glad that I did it because I really haven't missed work at all (Participant 4).

Other participants made the decision to be more available as caregiver, spending less time working outside the home even though it added an additional financial burden to their lives.

That [more income] would be good, just weight off of me. I mean not having to worry about that. Worry that I need to go to work, I need to go to work (Participant 3).

Military to civilian navigation. Moving from being active duty military to the veteran world was yet another point in time where participants and their veteran spouses had to redefine themselves and what they did. For example, one participant verbalized her experience with the shift:

People say being in the military is a hard job. Being *married* to someone in the military is a hard job while they are in and afterwards it is even worse. They, ummm, being a soldier's, wife wasn't as hard. He had to get up, go to PT, you know, told what to do all day, come home eat dinner go to bed. Same old routine over and over. When he got out and had time to think and wasn't being told what to do, that's when things did a 180 and it was unbelievably hard (Participant 6).

The transition from military life to civilian life was as much a struggle for the veteran as it was for his spouse, but it was frequently the spouse who was left assisting her veteran partner with the difficulties inherent in the change, of redefining himself as civilian:

Soldiers who go to war, 24/7 when you are a soldier, male or female, somebody always tells you what to do; when to eat, when to work, when to [physical training], when to go to bed, what to do, when you can go to the bathroom, when you are to get a shower . . . They can't throw that off just because they come home . . . They look at you and go, 'What do we do?' They are out of the Army. 'Who's gonna tell us when to eat? Who's gonna tell us what to do?' We don't have that structure of somebody saying, 'You have to do this now' (Participant 7).

This particular participant (7) managed her veteran's transition difficulties with a very matter-of-fact approach telling him, "I'll keep you in check. I am going to be your backbone and I'll be your support and you're going to be fine." I put my foot down and that was it."

The most salient descriptor of engaging in the task of moving from the military life to civilian life was provided by Participant Five who likened her experience to a geographic shift:

There needs to be some real civilization between that. I mean I say it's like going from a third world country to coming to America.

The time, energy, and cost to the participants as they worked to figure out how to navigate the "new" non-military world was extraordinary.

Other study participants found the move from the military way of doing things to the VA way of doing things very challenging, but they had had previous experience "bucking the system" while in the military. Generally, within the military there is a certain procedure for navigating the system and that process is followed by one and all. A number of wives came to the conclusion that they were not going to be able to access the care their husbands needed by simply engaging in business as usual. They redefined what it meant to be a "good wife" in the military:

In the Army when they tell you, 'No' it means 'No.' You don't go up the ladder. You don't write letters. You don't, you know you don't do that . . . He always made me feel like I was doing wrong. Like if I went above somebody's head because I didn't like the answer they gave me, I was like, 'Okay, who is your supervisor? I will take this up the ladder and get some resolution.' But like now [the veteran said to her], 'I'm glad you advocated. I'm glad you stayed. I'm glad you did your research. I'm glad you are smart.'

And so that stuff like really validates the stuff I did during the process because... It's like, like in a way I feel like I saved him (Participant 5).

The difficulties one participant experienced immediately after her husband was injured eventually shaped and molded her into the person she is today. Initially, as a very young adult, she stated she was "hot headed and mouthy." She sees herself now as "improving a ton" and went on to advocate for his medical discharge from the military:

I dealt with all those people in his unit, all those people in the Warrior Transition Battalion. I have fought these people every step of the way . . . So that was a challenge there because we've dealt with those people [military] throughout trying to get him out of the military. Something, a very long process of him having to go through that and me, I mean I was the beast. I mean 'Beware. You've already hurt him once and you're not going to again' kind of thing. It was very, very rough for us to go through that . . . very rough because he [husband] wasn't happy with me every time I would contact his Sergeant or his Jump Master and then, his Captain. You just don't do that. Wives do not do that in the military. You do not. You do not contact any of them (Participant 3).

She spoke further about her motivations to redefine her role in the process:

Well, they almost killed him once so they were not going to do it again. One of yours was injured and it's you all's fault. He shouldn't have jumped [parachuted]. And you're not, this is not happening again. You're not gonna hurt him. And that was it for me. I mean they were not going to continue to sit there and continue to hurt him.

The long, frequently convoluted process of obtaining a medical discharge from the military was viewed by the participants as the training ground for learning how to navigate the VA system. The time spent dealing with the rules and regulations of military life ultimately

assisted in the transformation of the participants from “military wife” to patient advocate and patient caregiver.

The work of redefining self is an ongoing endeavor in the life process of growth and development for all persons; roles shift, careers change, and environments are altered. However, in the world of this sample, the course of redefining self is accelerated at a pace that surpasses the norm. The work of finding self, reinterpreting self, others, and the world did not follow a straight path with a clear ending and beginning. Rather, it was a course plotted out on a landscape that was ever changing; a path on shifting sands.

“I’m on an island by myself”: Alone. Some of the most moving narrative of the partners was around their sense of “aloneness.” There was, for most, a perception that they were in it by themselves without the support of family, friends, VA providers, or community:

I feel like I am doing it by myself because I have to be the responsible one, right?
(Participant 2).

You’ve got to be the go-getter. You don’t have anybody else to help you out. You’ve got to go. There’s nobody else. You’ve got to do it. You’ve got to be the strong one for your family now (Participant 3).

We are basically on our own (Participant 1).

Nobody gave us [spouses] a booklet saying, ‘Your husband is pretty, pretty disabled. Here’s all the stuff that you are going to have to deal with.’ We’ve all had to figure it out on our own and figure out how to manage it (Participant 6).

There is nobody I can call and vent to. Nobody (Participant 7).

For some, this state of “alone” came to be through the post combat, post injury behavioral and emotional changes in their veteran spouses. The veterans’ inability to feel safe in certain social situations slowly narrowed the world of the couples. Additionally, a number of the participants found that their pre-deployment friends were markedly uncomfortable around the veteran upon his return home:

As far as other friends, a lot of them, me and him both had mutual friends that we’ve had for a very long time that we’ve just kinda of had to, let go because they just don’t understand you know, how he is, how different he’s become. So, we’ve just kind of withered everybody away (Participant 3).

When he first came home, he pretty much alienated everybody who we were friends with. He pushed everybody away . . . He pretty much alienated everybody and that made me alienate people not by choice, but just kind of like he, he would say something that would offend somebody so much that it was like ‘Whoa!’ They didn’t want to talk to us anymore (Participant 5).

The expressed sense of being in it alone was very difficult for a few of the spouses in particular. They were engaged in active attempts to expand their social circles, but found it to be very challenging for a variety of reasons which ranged from the inability to leave their husbands alone for any length of time so they could get out and socialize on their own to their husbands’ averseness to new people and new places.

I’m trying, I’m trying to connect with other people because it’s important and I feel like I’ve been ostracized on an island all by myself because he is so suspicious of people and we can’t have people over to our house because he doesn’t know who they are . . . It’s so

hard to make friends and be friends with people because we've been on this little island of 'It's only going to be us. It's going to be my little circle' (Participant 5).

We have been to the movies; we have been out to eat. Basically, trying to do things in public is a challenge so to say, because, you have a lot of people in public, of course. And he cannot stand to feel like he is being closed in. So there are times when we don't go out at all . . . I mean do anything at all whatsoever (Participant 1).

My mom and my brother were here [at their home] and we were all upstairs goofing off and he just wanted to sit down here [downstairs den] and be alone and those, I guess that's what I have more trouble with. I'm usually pretty upbeat and like to be around people and he, he hates to be in big crowds. It's just very, well, it's very hard for him (Participant 4).

A few of the women were reluctant to reach out to friends and family as their husbands had made it clear that they did not want anyone else around. A multitude of federal agencies and non-profit organizations exist solely to provide social support and activities for veterans and their families. However, locating the appropriate one targeted to meet the specific needs of each individual veteran's family was overwhelming for some as there were too many agencies to investigate and too many numerous forms to complete with no guarantee that the support would materialize. Others simply didn't know where to turn for help and support or found that they met unanticipated roadblocks when they did reach out:

There were numerous calls to his family saying, 'I need help. Can you come up and see us?' You know, 'I need help with him.' But when his family comes . . . he puts on a very

strong face and a very, a mask that is very different from what's really going on when his family [visits] here. The only reason his family knows what's going on is because I have warned them because I'm at the point to where I can't deal with things by myself and keep being the person that I think I am. I'm losing myself slowly (Participant 6).

The need for more contact with the "outside world" was shared by all participants, across all age spans. The youngest participant was 23 years old and mentioned that while she would like to see more visits from family members, "His family won't come over here; it would be a big help if they would just come over here," she went on to talk that her contentment in being with her nuclear family. This was all said against a backdrop of her talking about her "former" self, prior to her husband's TBI:

What made me happy before was being able to go out and socialize and hang out with friends. I'm a big socializer. I love to socialize. I love to be out. Totally opposite of him, especially now, but I've kind of changed all that because it is my family [husband and son]. My family is what matters the most to me. The most important . . . so as long as they're happy, I am good to go. Good to go (Participant 3).

For one participant, the need to reach out for help or to share the burden with others was tempered by a desire to protect others and self, but it left her isolated:

I really, people have asked me, I don't, I just really keep it [stress] in. I don't talk too much. You can see how I am rattling on to you. You can tell that I don't talk to a lot of people or somebody. . . I don't like to. Because, why, I mean I'm not, because they would probably worry, they would probably feel sorry for me and I don't want them to feel sorry for me. I am who I am (Participant 2).

Saying nothing, maintaining a life of physical isolation from others and veritable silence regarding the difficulties faced was described as challenging in the best of the unpredictable day-to-day, but came to be unbearable in times of extreme crisis. Four of the seven participants had spouses who either threatened suicide or actively attempted suicide. It was during those time periods that their loneliness was most keenly felt. One of the participants (6) had been “Trying to suffer in silence and deal with it on my own” until her veteran partner’s third suicide attempt. At that point, she reached out:

Okay, I can’t do this anymore by myself . . . I made a post on Facebook about not being able to do this without asking for help anymore. I basically made my cry for help to my friends and family. And I had just an outpouring, an enormous outpouring of phone calls and text messages and emails and comments and people would come over . . . I reached out and there were hands, they were more than willing to grab ahold and say, ‘I’m here to help you’ (Participant 6).

After she had clearly expressed how she was suffering alone, I asked her what took so long to ask for help. She said she had talked about just that with the spouse of another veteran and they came to the following conclusion:

It is hard and not a lot of people understand. If they do, they are too afraid to talk about it. They have a fear. They don’t want to be looked down upon. They don’t want to be put in a category or stereotyped or labeled. That’s right, because I have felt that way for this entire time until I said, ‘I can’t do this anymore myself’ (Participant 6).

VA and military systems of care. The VA system of care left some partners feeling abandoned as calls placed were not returned; care was simply not available in a manner that met

the needs of the veteran and his family. The sense of being deserted by the military and the VA began the day the service member separated:

He was med-boarded out and ‘His hips, they’ll just get him new hips and everything is going to be great. You are now out of the military.’ I was like, ‘Great. This is wonderful. We will have our lives back.’ And there was nobody to pick us up on the other side saying, ‘Okay, this is what you need to do,’ and holding our hands to get us through. . . My lack, I guess probably being naïve ‘Oh, yeah. They are going to . . . I’m going to go walk into the VA and they are going to say, ‘What can we do for you?’ You know, it’s, that’s not totally, not even close to how it works. I hope it works better now, but when we got out it was a complete and utter mess (Participant 5).

Others received excellent medical care while in the military, made important connections with providers, but once out of the military they felt forsaken by the VA system which was intended to be their source of care and support:

The next day, I called everybody I could at [my husband’s former] base. Because those were the only people I know because at the VA, nobody, his caseworker would not call me back, help me out, nothing. Here in the [city] VA, they had no answers, no answers (Participant 3).

This same woman went on to describe how she was able to secure care for her husband using military health care providers rather than VA providers:

I was trying to get ahold of him [former military neuropsychiatric MD] and I was trying to get ahold of him because he was the one who knew everything. He called me back. I was very surprised. He explained to me what I had to do. . . His doctor helped me out tremendously by telling me, ‘It’s step by step and it’s baby step by baby step. And you’ll

get to where you can take giant steps, but it will be a long process' and it was . . . And his doctor really helped me out (Participant 3).

Participant Five spoke at length about her attempts to engage the VA system to obtain what she saw as appropriate care for her veteran spouse. The couple eventually left the VA system of care and sought care in their local community where they found providers who "understood":

Well, in [city] I tried to get him some one-on-one therapy and to try to get his med stabilization and nothing was working . . . We really had to push the VA out because I didn't feel like they were doing enough for him and I kept getting this response of 'Well, our system is really flooded and we don't have the resources.' And there came a point where that was just not an acceptable answer and I didn't have time to deal with the bureaucracy of getting, you know, the treatment. So we had to find therapist, we had to find psychiatrists, we had to find counselors, readjustment counselors, we had to find a really good marriage therapist who was combat or had combat experience and wasn't looking at it from, like, your average Jack and Jill marriage. Somebody who really understood the issues going on (Participant 5).

She elaborated further describing what it was like for her when her husband first separated from the military:

For me there was nothing. It was like one day I woke up and I was, the caregiver, the wife, spouse, the person who does all the paperwork, pays the bills, like it was all on me. Basically I was alone. That's how I felt. I felt very alone and very misguide about 'Oh, here is your file. Congratulations. You are separated. Here's your whole life. You don't get free housing anymore. You don't get VA. You don't get BAS [Basic Allowance for

Subsistence]. You don't get all this stuff anymore. You've got to fend for yourself and by the way, your husband is disabled and good luck with that.' It's not like he came out and could go get a job, he's fine. He was extremely broken and because he was broken, they didn't want him anymore was how I felt. And I still feel that way. I feel like they used him until he wasn't good enough and then they were like, 'Yeah. Here you go. Good luck with that. Oh, and by the way, you are probably not going to be able to work and you are going to have to fill out all the paperwork to figure out how to survive' (Participant 5).

While other participants did not describe their experiences with separating and the VA system of care in frankly negative terms, one participant (7) responded to the initial "What stands out to?" question with:

They fall through the cracks. They [the soldier] don't always get . . . our first person we went and talked to our first therapist . . . said 'You are the way you are because you want to be.' And we didn't go back. There was no help because they didn't know how to help him (Participant 7).

Accessing care through the VA system did not come with a guarantee that the same provider would continue to be available. When inevitable staff changes happened, the impact on the participants included isolation from a spouses' group, no timely access to a therapist, and trying to manage challenges in a marriage without the input from a professional:

That place, at the VA Center, where he would go in and see his therapist and then we [spouses] would either have a meeting or I would go in and talk to one of the ladies. And then his therapist got a better job and left. And that threw him. He said, 'I'm not going back, I am not doing nothing.' So he refused to go back over there and he was getting worse and worse and we was fighting and carryin' on and stuff and then finally I said,

‘We’ve got to do something.’ So we got hooked up over here [different VA Clinic] with her for the marriage (Participant 2).

One must also keep in mind that the participants in this study had also lost the men they knew from the time before the war. There is no way of really knowing what the details of the participants’ marital life consisted of prior to the war, but following deployment most of the intimate conversations with spouses had to be initiated with great caution for fear of exacerbating an already trying situation. A number of the participants simply avoided discussing anything of substance with their spouse, fearful of the emotional backlash. One participant discussed this in terms of how a conversation evolved after her husband’s suicide attempt:

I’m supposed to be strong . . . and he’s like, that’s when he went into, instead of where I was hoping for, ‘Honey, it’s okay, we’ll get through this.’ I got, ‘This is all my fault. If I didn’t do this you wouldn’t have hurt [tripped on the stairs] yourself. You wouldn’t be like this.’ So that made it worse so within an instant of that coming out of his mouth I immediately stopped crying, sucked it all up and put my armor of war on and off I went, commenced to doing what I’m supposed to be doing. He said, ‘We need to talk about this.’ I said, ‘No. Um un. Nope. I can’t talk to you about this. I cannot talk to you about how I’m feeling with all of this without knowing that it is going to put you in some kind of depression that is going to make me feel even guiltier.’ And he said, ‘Wow. That’s how you really feel?’ I said, ‘Yeah. That’s how I really feel. I wasn’t ready for you to come home [from hospital after suicide attempt]. I wasn’t ready to have [your depression] in my face already . . . He said, ‘Well, what can we do?’ And I said, ‘I don’t know. I don’t know because it’s not like I can pack my bag and go to my sister’s for a week without thinking that you are going to try to kill yourself again.’ I said, ‘And then I

will be the cause of it. You are putting me in a position I don't know what to do. I don't want to be in this relationship. I can't go through this. I cannot go through this. You are bringing me down and I can't do it' (Participant 6).

Trying to have a conversation with him is almost impossible [due to thinking capabilities, reasoning, and inability to focus] (Participant 2).

They [the veterans] aren't just forgetting you [spouses] and blowing you off. Because that is kind of how I felt for a while. What I say goes in one ear and out the other. Nobody cares. That's what I used to tell him all the time 'Nobody cares what I say', but being able to talk to the doctors and them say, 'Ok, this a problem and this is a problem and he has a problem in these areas and problems expressing himself.' Which was a good one because I was like 'He never talks to me. He never just tells me what's on his mind.' And they were like, 'He can't always tell you.' And I was like, 'Why not?' . . . It's not just that he is going to go through their 12 week program and be healed. This is something where we have to adapt to for the rest of our lives (Participant 4).

Stifling emotions, filtering thoughts, and simply not raising troubling relationship issues becomes routine for some. Taking the path of least resistance prevents potential emotionally charged conversations, but also leaves a patina of frustration and loneliness coating the marital relationship.

See, like I told you earlier, if I was to address it [her frustrations with veteran's behavior], even although it, it's in a real calm talking voice, it would turn to escalation argument. So to keep that from happening, I really don't say anything. I don't say anything to him about it (Participant 1).

For the participants in this study, the sense of aloneness started in marital relationships and rippled through their entire lives like molasses; sticking to every surface, difficult to peel away without the proper tools. For at least some of them, talking with the researcher was the most they had opened up about their lives with anyone, and that discussion came at great risk, and fears about the researcher's safety and trustworthiness. The fact that these interviews were so hard won speaks to the participants' reticence to share about their challenged lives. The rich and unsparing content of their narratives speaks to their desire to connect and unburden themselves with someone who will not judge.

***“I won’t give up on him, ever”*: Commitment and perseverance.** The study participants had been partnered with their veteran spouses anywhere from four to thirty-three years. All but one described a vision of the future which included their spouse. In fact, a number of the women had very positive attitudes about their futures which included plans to stay married to their veteran partner. The youngest study participant was twenty-three years old, married for five years, and was extraordinarily clear in this regard:

You know, your challenges are going to the grocery store, trying to manage everything on your own with a family and it’s not the easiest thing to do, but we get through it. We do . . . To me, no matter if he’s not remembering for 30 seconds, every day I will still be here with him. We’ll make fun of it like we do now. We’ll make fun of it somehow, but I won’t give up on him. Ever (Participant 3).

Similarly, Participant Four described her sense of where she and her spouse are as a couple and where she sees them in the future:

I mean, we can work with this because we're talking and we're getting along and we're working through it together and that's fine . . . I plan to be married to him for the rest of my life so we've got to make the best of it (Participant 4).

The oldest participant who was 53 and who had been married for over 33 years put it like this:

I am who I am. I'm gonna do what I am gonna do 'til I die and that's it. I am going to do all I can do, you know? In the marriage and what I can do for him to try and help him no matter what I have to do. . . And the good part would be, thank God I love him (Participant 2).

Other participants did not come across quite as direct or tender when describing their sense of dedication to their partners. Yet the point was made in a style true to who they were:

Mine is not going to be a statistic . . . He is not, like I told him, 'I'm not giving him an option to give up. . . Dying is not part of the plan. You're not getting' off that easy.' I did not give him a 'check out free' card and he better think about that. And I tell him that. He ain't going nowhere. He'll be there . . . Don't give up. You're it. If you're the spouse, you're it (Participant 7).

There was one participant who framed commitment and perseverance in terms of herself and her measure of her abilities to cope with a continually challenging partnership:

I'm not a quitter so I was determined, I'm still determined, not quite as much as I used to be, to try to keep things moving forward to make things work to try to help him and get, not necessarily over this, but get to a point to where he can say, 'Okay, I have this issue. It's okay. I can live with this and move forward.' And that's kind of where we are stuck at . . . I have never experienced the plethora of emotions that I have experienced. I mean, I have felt love and hatred all in the same moment and just been absolutely torn as

wanting to just run up and cuddle and try to hug things away, but at the same time, want to run away and say, ‘What the hell was I thinking, getting into this mess? This is more than I can handle.’ It’s not easy (Participant 6).

A number of participants implied commitment as they spoke in terms of a shared future with their veteran spouse. Participant Five’s descriptions of what she and her husband are doing to move forward as a couple in partnership provided a small window into the work it has taken to maintain their marriage:

We have little lists that our marriage therapist put together that, well, we actually do the legwork, but he asks the questions like, ‘What makes you feel special today? What’s the best part of your day? What’s the worst part of your day?’ At the end of the day, we always ask each other, ‘What could I do different?’ We’ve made huge, huge progress (Participant 5).

Throughout the interviews, there was generally a pervasive thread of life moving forward. “Life goes on; you’ve got to keep living. You can’t let those things hold you back from living every day” (Participant 3).

We don’t need to prove anything to anybody. I don’t have to, our life is what it is and I don’t want people to feel sorry for us. I don’t want people to be like, ‘Oh, well, that is such a bad thing that happened to you.’ Yea, it’s bad and we have to deal with it, but life still has to go on. We can’t just sit and be sad all the time (Participant 4).

This was not the life, nor the partnership that the women envisioned when they first married, but for the large majority, “This is number one, above all” (Participant 3).

Summary

In this chapter, the study participants described their personal experiences of living with a veteran with a TBI. The prevailing theme was one of change and difference which essentially undergirded the remaining figural themes of; alone, redefinition of self, making sense of it, and commitment. All of the previously mentioned five themes wove their way into a ground identified as shifting sands. The figural themes and the ground theme worked in concert with one another, dependent upon and defined by each other.

CHAPTER 5

Discussion

This chapter will begin with a brief summary of both the research approach and the major findings of the study. Following this will be an exploration of Merleau-Ponty's existential life grounds and their relationship to the research findings. Subsequent to that will be a brief analysis of the difficulty with participant recruitment for the study. Next will be a discussion of the study's findings and its intersection to the research literature on partners of individuals with traumatic brain injuries (TBI). Implications for nursing practice, research, education, and policy will then be presented as will recommendations of potential nursing theories specific to this line of research. The strengths and limitations of the study will be noted prior to moving on to future directions of research. The chapter will conclude with my personal reflections on both the research itself as well as the experience of doing the same.

Introduction

The purpose of this phenomenological study was to describe the lived experience of the partners of veterans who acquired a TBI through their military service in Operation Iraqi Freedom (OIF) two or more years prior to the study. To that end, the qualitative research based on the philosophy of Merleau-Ponty (1945/1962) and using the process of Thomas and Pollio (2002) was undertaken. It consisted of open ended interviews with seven partners of Iraq combat veterans with TBIs. The perceptions provided by the study participants were gathered to assist in answering the following research question:

- What is the lived experience of the partners of Iraq war veterans with a TBI acquired during their deployment two or more years ago?

This research was intended to add to the small, but growing body of knowledge regarding the lived experiences and unique needs of the partners of combat veterans with TBIs.

Participant recruitment was a major challenge, with evidence suggesting it was related to reasons of trust and safety. Seven female spouses of male veterans from OIF met with the researcher for interviews lasting from 32 minutes to 73 minutes. All of the interviews were taped with a digital tape player and transcribed. Following the process described by Thomas and Pollio (2002) the narratives were read a number of times in concert with others and singularly. Through this method, the co-created figures and ground were identified. The contextual ground was viewed as a construct resembling “Shifting Sands”; never firm, always changing, with no discernible pattern. The figural themes were primarily those in the existential life theme of “Other” or lived human relation. The thematic structures were designated as:

- “*The Person I Married is Not the Person I See*”: Change and Difference
- “*They Just Don’t Understand*”: Making Sense of the World
- “*It Transforms All of You*”: Redefinition of Self
- “*I’m on an Island By Myself*”: Alone
- “*I Won’t Give Up on Him, Ever*”: Commitment and Perseverance

Exemplars were provided to support all five of the thematic structures.

Existential Figure and Ground

The goal of the phenomenological interview was to gain an understanding of each individual participant’s perceptions of their personal contextual lived experiences. All of the participants shared experiences in the military subculture with its cultural norms, unique customs, and processes of deployments. While this was not the defining aspect of the participants’ shared experiences, it contributed to the construct of their common ground.

Merleau-Ponty viewed human behavior as occurring in the situational context of experience (Thomas, 2005). The participants shared the culture and context of being spouses to military service personnel with all of the ensuing uncertainty that comes from that experience. This includes unpredictable lengthy deployments, insecurity regarding their spouses' safe return, frequent geographic moves as part and parcel of military life, and essential powerlessness in impacting the structural landscape of military life which waxes and wanes dependent on politics, policy, and forces beyond the control of one individual.

In contrast to the variables of unpredictability found in the military, the participants also spoke of the comfort and security they found in being part of the military culture. For many, the military structure, rules, and regulations served to add an element of certainty that was lost once the couple separated from the armed forces. In the military, there were set expectations around the course of erratic events, lending a known quality to the days. The civilian world was often experienced as unpredictably unpredictable which marked a distinct difference between the two worlds.

The fluidity and ambiguity of human perception stems from the fact that perception itself is not passive in nature, but rather a result of active engagement with the surrounding context, the world (Matthews, 2006). As individuals' worlds shift and change, so does their perception of their lived experience. The co-construction occurring between the individual and their world leads to the co-creation of a figure only visible against the backdrop of a ground (Merleau-Ponty, 1945/1962). All of the major existential elements: World, Time, Body, and Other People are given structure and shape in relationship to the context of culture (Thomas, 2005).

Other. For the participants in this study, the primary existential element was that of Other People. All of the identified themes strongly aligned with the concept of relationship with other human beings, with culture, and with society as a whole. The participants described themselves in terms of their relationships with their veteran husbands. In essence, they viewed themselves in a manner which was filtered through the lens colored by the needs of their spouses. Thus, in their own words, they became their husbands' support, parent, caregiver, advocate, backbone, friend, protector, buffer, and partner. The interface with the "knot of relations" of Other People appeared to be restricted to those present in the veterans' post-deployment, post TBI world. This then led the participants' to describe themselves as shifting and shrinking in the shadow of their veteran partners' needs: "I have no independence to try to just normally, just being a woman . . . I have got to try and rearrange my whole life . . . It's like I have to stop living" (Participant 2).

Caregiver burden. All seven of the women discussed their efforts to maintain a clear sense of who they were, separate from their veteran spouse. Caregiver burden, defined in Chapter 2 as the caregivers' perception of the subjective and objective consequences of the emotional, financial, physical, and social demands required in the provision of care for their partners, appears to have an influence on sense of self as one separate from the veteran. Participant Six, who stated "I'm losing myself slowly" related this to the efforts it took to take care of her husband. No quantitative measurement of caregiver burden was done in this study, but the qualitative narratives revealed multiple expressions of caregiver burden. To a large degree, the individual perceptions around caregiving burden dictated the extent to which the women felt "lost" to the world of their injured spouses. Women who had utilized a wide array of coping skills seemed to have less of a sense of caregiver burden which somehow allowed them to

be more connected to their “former” world of Other People and less consumed by the Other as primarily dictated by the needs of their spouses.

Alone. The significant and serious social losses incurred by the women around Other People would seemingly make them more vulnerable to stress, depression, anxiety, social isolation, frustration, and ultimately, loneliness. In fact, all of the participants expressed perceptions of “alone” in its myriad variations which lead to a structural theme labeled “*I’m on an Island by Myself*”: Alone. This, too, finds a place in the existential element of Other People. If one possesses the sense of being alone, defined as “without help from others: without help or support from anybody or anything else” (Encarta Dictionary, 2009) then one must have had the opportunity to seek connections from others prior to finding others inaccessible (Merleau-Ponty, 1945/1962). The participants’ expressions of “alone” were frank and pointed as they frequently saw themselves apart from family, friends, health care providers, and peers.

Couplehood. To a large extent, all the participants described a degree of feeling alienated from the husband they once knew. This seemed to contribute to their sense of isolation and abandonment. There were multiple instances when the women described their veteran spouse pushing them away. For some, this was a distinct verbal direction given to them in clear concise language that was unmistakable in message. Others had to contend with subtler variations of the message leading them to alter behaviors and stifle conversations which eventually developed into a sense of being “apart from” their intimate partner, the man they married. Merleau-Ponty speaks of the body as the vehicle to which one has access to the world. In light of such, the “walking on eggshells,” reported by a few participants is emblematic of just how they, as committed partners, were perceiving life with their partners.

Families. The themes of “Commitment and Perseverance,” “Change and Difference,” and “Making Sense of the World” lean heavily towards the existential theme of Other People. The relational pieces were primary to how the participants’ experienced and described their lives. Moving outward from the intimate partnership and nuclear family, one begins to see how the veterans’ TBI deeply affected the totality of the partners’ lives. One participant had remarked, “It disrupts everything, everything.” She couldn’t have been more precise if she had spent weeks thinking about it. To varying degrees, relationships with extended families were disturbed in significant ways. Not all of the women were estranged from extended family, but all tempered previous patterns of engagement with family members either in an effort to protect the family members or to protect their husbands. The sense of social isolation from family was profound in three of the women. One woman described how she felt compelled to shield her mother from the extreme difficulties she experienced living with her injured husband. Another partner spoke of the shame she experienced around her husband’s invisible neurocognitive injuries which led to verbally aggressive outbursts and socially unacceptable behaviors. She put vast amounts of space between herself and her mother in an attempt to contain her own sense of shame. Still others found that their extended families were the ones pulling back and withdrawing from ongoing social contact. Invitations to come by for meals were rebuffed leaving the veteran couple to see extended family only at holiday meals held at the homes of others. The scenario grew into one consisting of the veteran’s spouse offering and extending care to the extended family rather than the seemingly more logical reverse. The disruption or change of “normal” family relationships tended to add another layer of work to the identified themes of “Redefining Self,” “Alone,” and “Making Sense of the World.”

Within the constructed lives of the women, relationship disturbances continued to fan outward from the core of nuclear and extended family to impact the usual interfaces with friends, work colleagues, and “the world.” To some extent, relationships with old friends followed a path similar to that constructed between the individual women and their families; it was often shame, overwhelming stress, caregiving burden, and need to protect which drove the wedge between the two parties. An added element serving to instigate a keen sense of alienation between the women and their friends and co-workers was the women’s dismay around being misunderstood. Two women described incidents when they told co-workers and neighbors about their husbands returning gallon containers of milk to the kitchen cabinet rather than the refrigerator. The co-workers and neighbor, who saw their own partners in the actions of memory loss and disorganization related to a simple daily task, invalidated the women’s daily experiences of living with someone with a TBI. These small social interchanges ultimately added to the constriction of the women’s worlds as they were left with an “Okay, I can’t talk to them.” The work put forth to maintain social connections and uphold prior relationships was exhausting and at times, humiliating as it refuted the day-to-day of life with a wounded veteran partner. The women found that their turning to expand the potential positive potential of Other People as they contributed to sustaining the new normal of the women, sometimes accomplished just the opposite.

General public. The existential element of Other People was also touched upon as the women verbalized a need to educate the greater public about TBIs and veterans. The collective perceptions of the women suggest they believed the general populous has not only forgotten about the wars in Iraq and Afghanistan, but have also forgotten the men and women who were deployed and returned home with TBIs and PTSD. One woman made a particularly astute

statement in saying that the general public needs to wake up and learn more about the veterans who returned from war with TBIs and PTSD. She said society will pay now or pay later, referencing the need for systems of care that support the mental health needs of veterans. She used the example of a veteran “losing it” at a fast food establishment when his order was not correctly filled. Her husband had done exactly that about two years prior and she had recently witnessed another veteran doing exactly the same thing. This stuck with her, making a substantial impact on her perceptions of how her veteran husband was seen by those outside her self-described ostracism on “an island all by myself.” Two women spoke specifically of “educating the world” about the military and TBIs. This was a noble intention, but it seemed as if they were struggling to simply educate their extended family and friends while they themselves had only recently come to their own understanding of TBIs. Clearly, the perceptions of those outside their sphere of existence mattered to them. If anything, the desire to somehow further educate the public on TBIs was indicative of the need to “be heard” and understood and supported as they strove to gain footing within their own worlds.

Childhood experiences. Merleau-Ponty (1945/1962) writes of the co-construction between people and the worlds they inhabit. As mentioned earlier, three of the women in the study had very difficult childhoods inclusive of poverty, abuse, and the early death of a parent. These women chose to view their childhood experiences in a positive light, stating they made them strong for the task currently at hand; being the partner of a veteran with a TBI. The significance of strength hard won was not lost on them, but they did not express an understanding of how their prior childhood experiences of raising younger siblings, caring for widowed fathers, and being left to pick up the pieces after frank abuse may have left them more inclined to take on caretaking roles as adults. In short, whether they were aware of it or not, it

was a role they knew and knew well. The present day situational context must have had a sense of familiarity as parts of it rang true to contextual grounds of the uncertainty experienced in childhood. The turn towards the existential element of Other People from a stance of need was likely shaped at an earlier age and was reinforced with the experience of partnering with someone in frank need of care.

Time. The themes of “Change and Difference” and “Making Sense of the World” contain elements of Time as the before and after quality was woven throughout the narratives; life before the veterans’ TBI, and life after. The participants’ personal experiences of time reflected the four major themes noted by Thomas and Pollio (2002): Change and Continuity, Limits and Choices, Now or Never, Fast and Slow. Most of the women used the marker of the TBI injury as the fulcrum point for life as it was or used to be, and life now labeled as the “new normal.” As one would expect, the unpredictable nature of the TBI symptoms affected the theme of Fast/Slow imbuing it with qualities that allowed for a swiveling cyclical motion of sorts; agonizingly slow at points and all too fast paced to endure at others. The time element of Limits and Choices appeared in a multitude of descriptions including those on career changes, time spent with nuclear families, and time alone. The scarcity of time alone to pursue activities for self and self alone points to the limits imposed by the acts of caring for veteran partners. Time was rarely alluded to outright, but the frequent references to the continual changes experienced in the day-to-day contribute to the importance of Time as an existential element.

Body and World. The element of Body was found in a limited fashion in the narratives, but present when the participants’ told of their fatigue and pervasive worry. The existential element of World or Space was partially supported by many of the women who, at their veteran partners’ insistence, lived in rural areas to decrease the possibility of encountering anything

resembling groups of unknown people. The discussion around this was never extensive, generally mentioned in passing, but remains significant as it is indicative of the safety sought in the construction of the wider Place and Space. One participant did talk of her nightly hopes that her husband would go to bed early and not insist that she do the same. He was particularly guarded when it came to her physical safety and felt more at ease when she was close by. She longed for time by herself to watch T.V. alone in her home, once a place of retreat for her and currently more akin to a prison.

Overall, the five figural themes congregated in the existential element of Other People and assumed their unique shapes when placed upon the ground identified as that of Shifting Sands. All the participants shared cultural and historical experiences, primarily built around the time spent as the wife of a military service member deployed to an area of combat which profoundly affected the co-construction of their current embodiment of the world.

Recruitment Difficulty

As discussed in Chapter 3, participant recruitment was a major unanticipated challenge throughout the research process. The detailed progression of recruitment efforts used for this study has already been presented in Chapter 3, but it seems judicious to further explore the possible reasons for the difficulties encountered.

Significant thought was put into the process of participant recruitment beginning with considering whether or not to seek Institutional Review Board (IRB) approval from the regional Veterans Affairs Medical Center's Research and Development Department. IRB approval from the VA would have meant that active recruitment could have taken place in the specialty clinics designed to serve Iraq and Afghan veterans and through the VA Caregiver Support Program. Early on, a decision was made to not seek the authorization of the VA's IRB as my prior

employment in the VA system led me to believe that potential participants may be more likely to trust someone outside of the VA system. I also had an unsubstantiated opinion that VA system may not be eager to support my proposed research. Those in the military are considered to be “institutionally vulnerable” (University of South FL, n.d.) necessitating additional safeguards prior to embarking on any research involving human subjects. However, I was aware that the family members of active duty military personnel do not fall into that same “institutionally vulnerable” category, nor do veterans and their families. With that knowledge, the only IRB review sought was that of the University of Tennessee Knoxville. By limiting the IRB process to my academic institution, I knew that likely I would be unable to enlist the assistance of either health care providers at the VA or those on the nearby military base in the recruitment of study participants.

The military, and by association the VA, has its own subculture, its own unique networks, and sense of belonging (Sherman & Bowling, 2011). Having never been in the military, I was not part of that system. When participant recruitment began, it had been two years since my last employment with the VA and while I remained in contact with a number of my former colleagues, in undertaking the research I was “outside” of that system as well. My ability to access entry points to the community of Iraq veteran partners was the first barrier to participant requirement. As time progressed, I made a number of contacts with those in the community who served veterans and their families. None of the contacts made to Veteran Service Organizations (VSO) yielded potential study participants. In retrospect, that was likely due to the lack of ongoing relationship between the VSOs and individual veterans’ families as the VSOs are generally serve as the point of contact for seeking service connection disability compensation with few younger veterans pursuing social connections with the groups.

The community contacts that did yield potential participants were through the efforts of individuals I personally knew who were currently in the VA or military system including a retired Air Force Lt. Col., an active duty Army Wounded Warrior representative, a retired Army chaplain with a clinical psychology degree now treating military families, and a local campus minister whose organization had grant money to put towards counseling and programming for military service personnel and their families. The only health care provider who was willing to actively recruit participants was the retired Air Force chaplain now a clinical psychologist. He had a practice close to a large military base and treats active duty military personnel, veterans, and their families for a wide range of behavioral health issues.

Interestingly, it was my role as a professional chaplain and not a nurse which appeared to be most valuable in solidifying connections. The professional world of ministers and chaplains engaged with members of the military seemed to have a profound understanding of the difficulties faced by military families and were more willing to “stick their neck out” to assist with research ultimately aimed at supporting military families. In the military, it is chaplains who are frequently the first point of contact for personnel experiencing mental health issues. Seeking care from medical providers such as behavioral health nurse practitioners, psychologists, or psychiatrists continues to carry stigma whereas chaplains are seen as “safe” and have the added bonus of maintaining confidentiality except in situations where there is imminent danger to self or others. Despite all of the military’s efforts to decrease stigma related to behavioral health services, it does not appear as if much progress has been made.

Vulnerable populations. The research literature contains writings on recruitment challenges in vulnerable populations, but as previously mentioned veteran partners were not technically a vulnerable population. It was only in hindsight that I began to explore that body of

literature, finding that there were many parallels with my recruitment experiences. In writing about issues in conducting research with vulnerable families, Demi and Warren (1995) identify possible impediments to participant recruitment as lack of trust, daily concerns which take precedent over participation in research, and a lack of awareness regarding the value of research. Many found that the use of a community gatekeeper to assist with identifying possible pathways to potential participants and subsequently endorse both the researcher and the value of the researcher was found to be beneficial (Demi & Warren, 1995; Horowitz, Ladden, & Moriarty, 2002; Pletsch, Howe, & Jenney, 1995). Reinforcing what I discovered through practice, the literature supports the work of building bridges within the sub-culture or community as a means to enhance the success of recruitment (Horwtiz et al., 2002).

The available literature on the willingness of the partners of veterans with neurocognitive injuries to participate in research is sparse, but there have been studies looking at the factors that exert a negative influence on caregivers' decisions to participate in research. The issues of stigma, mistrust of researchers, unmet service needs, and researchers who are unfamiliar with caregivers' cultural norms and values are possible reasons contributing the reluctance of caregivers to be part of ongoing research studies (Levkoff & Sanchez, 2004; Murphy et al., 2007; Sixsmith, Boneham, & Goldring, 2003). The women in this study were keen to share their stories with me once I was confirmed as safe by someone they trusted. However, it is apparent that there are multitude of veteran partners who did not chose to participate for reasons that can only be assumed, but likely were related to the same influences as noted by other caregivers in the research literature. If we are to truly begin to meet the needs of this population of veteran caregivers, there must be serious focused attention to determine the best possible process for study recruitment such that researchers are then able to capture and explore the widest possible

range of partner experiences. The establishment of a trusting relationship (Demi & Warren, 1995) over time may be one such avenue. Possibilities include the formation of relationships through longitudinal studies constructed to tract couples in the military starting at the time of enlistment, through deployments, and ultimately beyond the period of separation. This approach would yield a sample with wide demographic features and offer multiple options for further research.

Multiple opportunities exist for further research to better understand what motivates veterans' partners to join research studies. Additionally, there need to be studies directed at more fully comprehending the reasons this population chooses to decline opportunities to participate in research which has the potential to ultimately benefit them. My observations and conclusions, while no doubt valid for my experience, are likely but small pieces of the bigger picture.

Study Findings and Current Bodies of Knowledge

Military, civilian, and current research. Over the past two years, there has been a sharp increase in the attention given to the partners and families of veterans with injuries from the war in Iraq, particularly those with TBIs and PTSD. Multiple research studies are highlighting new findings regarding the pathophysiological mechanisms of injury which have significant impact on designing appropriate interventions and influencing the expected course of recovery for the veterans (Alford et al., 2011; Hemphill et al., 2011; MacDonald et al., 2011; Taylor et al., 2012; Wilk et al., 2012). In turn, these new research developments have the potential to inform a broader range of potential consequences for those closest to veterans; committed partners and family members.

As scientists explore the mechanism of action of blast injuries on the brains of military service personal, a smaller body of research is emerging regarding the challenges inherent in

being the spouse or partner of a veteran with a TBI. The findings of this study reinforce that which is known concerning being the partner of a veteran with a neurocognitive injury and adds to the literature on those who have a TBI and PTSD. While the original intent of this research was to seek participants whose partner had a TBI without excluding those whose partners had PTSD, it turned out that the 85% of the participants had partners with both a TBI and PTSD. The most recent research available in April of 2012 notes that this is not such an unusual occurrence as current estimates reveal that 73% of those with TBI also have a diagnosis of PTSD (Taylor et al., 2012). In light of that statistic, it is not unreasonable to assume that the participants in this study are to some degree, representative of the sample in terms of veteran partners' injuries.

The complexity of the veterans' neurocognitive injuries added to the couple's post-deployment integration and subsequent transition to civilian life, and the partner's abrupt transition to a variation of caregiver obviously had a greater impact on the experiences of veterans' partners than any single one of the aforementioned events would in isolation. It is this combination of events which leads to the unique perceptions of the women in this study.

The available military literature addressing spouses and partners touches on the identification of assessment tools for the well-being of spouses of veterans with PTSD (Hayes et al., 2010), the challenges of military couples post-deployment (Sherman & Bowling, 2011), the quantifying the distress of spouses of combat veterans with PTSD (Renshaw & Campbell, 2011), and the determination of the characteristics, type and quantity of care spouses are providing for veterans with TBIs (Griffin et al., 2011). However, I was unable to locate any literature addressing the complexity of issues faced by the participants in this study which is a composite of all the characteristics in the four samples utilized in the four distinct areas of research mentioned earlier.

Stress. It is already known that being the partner or spouse of a veteran with PTSD carries with it an enormous amount of stress for both parties (Calhoun et al., 2002; Dekel et al., 2005; Galovski & Lyons, 2004) so it comes as no surprise that the women in this study exhibited signs and symptoms of stress. Three of the women mentioned some sort of personal “break down” in passing, as if they were referencing the weather forecast for the following day. Even although the research was repeatedly explained as having a focus on *their experience* and not that of their veteran partner, the majority of the women explained their veteran partners’ emotional struggles in exquisite detail only speaking of their own crises well into the interview, usually in one or two sentences. Given the underlying element of trust between the women and myself, the body language and verbal signals displayed when noting their personal mental health difficulties, it was only with extreme caution that I sought further elaboration on their mental health issues. Had I had the opportunity to meet with them more than once, I would likely have been more comfortable exploring an area that appeared to be wrought with stigma and discomfort. As it was, the interview was singular in nature and I was especially sensitive to contributing to the women’s emotional distress by seeking clarification on topics they clearly did not want to discuss any further.

The classic Lazarus and Folkman (1984) stress, appraisal, and coping theoretical framework lent itself to an examination of the partners’ experience of living with a veteran with significant neurocognitive injuries. The women in this study had a range of environmental and situational variables which were antecedents to the development of their appraisal process and perceptions of stress. For most, the shared variable included financial concerns, military life, previous experiences in coping while their husbands were deployed in combat zones, loss of emotional support from their wounded husbands, and uncertainty regarding the trajectory and

degree of recovery. Obviously, each individual had their own unique environmental and situational life course which deeply affected their appraisal of their current situation. The extreme stress initially experienced by the women elicited coping responses intended to manage or alter the demands of the situation; problem-focused coping and efforts aimed at regulating their emotional reactions; emotion-focused coping

Of particular interest in this stress and coping discussion is the role of continued psycho-education aimed at problem-focused coping. A number of women spoke extensively of their efforts to learn about TBIs in general, combat acquired TBIs, expected symptoms, appropriate care, and general hallmarks on the path of recovery. The civilian TBI research literature contains a literature review of caregivers needs which revealed that the most common themes in terms of “needs” was the need for information related to the head injury, its longer term consequences, and skills for caregivers to use when adjusting to the changes of their loved ones (Sinnakaruppan & Williams, 2001). It is assumed that at some point, the women were provided with information from the military regarding the basics of TBI, but as one of the women pointed out, they received so much information at a time when they were still reeling from the news of their veteran husband’s injury that they were unable to process what they were told. Additionally, at that same time, they were trying to figure out the maze of medical discharge paperwork, determine how they were going to financial survive without their husband’s military salary, and begin the arduous process of filling out 30-40 page forms necessary to apply for service connection disability payments and enroll in the VA system of care. The provision of information needs to continue throughout the recovery and reintegration progress as opposed to be front loaded at the start of the transition. This fairly simple intervention would go a long way to influencing the

secondary appraisal process and hopefully, translate into lower levels of stress, greater problem-focused coping.

A more comprehensive method to target overall coping skills would likely prove to be more effective than any one singular approach. Research in areas addressing stress and coping in chronic illnesses such as those who are HIV+ has found that a group intervention, coping effectiveness training (CET) based on Lazarus and Folkman's stress and coping theory (1984) statistically impacts the use of positive coping strategies (Chesney, Chambers, Taylor, Johnson, & Folkman, 2003). The use of CET's 12 session training modules encompasses a range of cognitive behavioral treatments designed to assist participants with the stress appraisal process, teach emotion focused coping skills as well as provide added education and training in problem focused coping, assist with the development of social support avenues, and provide the participants with the tools to maintain their coping skills (Chesney, Folkman, Chambers, & Taylor, 2007). All of the women in this study could benefit greatly an evidence based approach to managing their overwhelming stress and improving their overall wellbeing.

Relationship satisfaction. Studies on relationship satisfaction in couples where one of them has PTSD have found the overall fulfillment of the couple to be negatively impacted (Goff et al., 2007; Renshaw et al., 2008). The findings of this study support those conclusions in that the women all experienced varying degrees of relationship satisfaction at different points in time. Those who had found it extremely challenging after the initial diagnosis seemed to adjust over time. This may have been a result of the improvements in their veteran partner, the natural course of transitioning and adjusting to a "new normal" or to their own better understanding of the pathophysiology of the injuries and symptoms. When they said "it's not me" in talking about being the recipient of their husbands' rants, they were in effect expressing a clear grasp of the

symptoms of TBIs and PTSD; global, diffuse, unpredictable, and not targeting any one individual person. The only participant who continued to experience a marked decrease in what could be loosely called relationship satisfaction was the one individual who married her veteran partner after the injury so she had no prior experience or history with her now “changed” spouse. Unlike the other women in the study, she was unable to reach back and recall the man she first loved in the early years of marriage, prior to the TBI and PTSD, allowing those memories to sustain the relationship during times of particular distress. For this participant, every difficult aspect of the relationship was measured against the same givens; the same two people exhibiting varying degrees of the same core behaviors and emotions.

The effect of a TBI on marital relationship satisfaction has been explored in the civilian brain injury literature through the use of the theory of ambiguous loss (Boss, 1999). This same theory was the foundation for examining how traumatic brain injuries impact the coping abilities of couples (Blieszner, Roberto, Wilcox, Barham, & Winston, 2007) which was linked to relationship satisfaction. The core of ambiguous loss revolves around an inconsistency in the psychological and physical presence of an individual. The women in this study all made reference to a “there but not there” quality in their husbands. The lack of clarity regarding the partners who were less reliable emotionally and unpredictably capable added a significant level of strain to the partnerships.

Citing research that implies that 50% of partnered couples will experience divorce after one member sustains a traumatic brain injury, Landau and Hissett (2008) used ambiguous loss theory to further examine the loss of self-identity or “boundary ambiguity and ambiguous loss” in the attempt to find a concept that may impact the rate of relational breakdown. My findings suggest that the loss of self-identity is indeed critically important to the maintenance of marital

relationships as the two women who openly struggled with “losing” themselves were the two who vocalized the most relationship distress.

Psychological distress. Not unexpected, spouses of veterans with PTSD frequently experience psychological distress and a sense of caregiver burden (Manguno-Mire et al., 2007). Neither of these concepts was directly measured in this study, but the narrative evidence points to a pervasive sense of psychological distress on the part of the women caring for veteran partners with PTSD and TBI. The one person in the study whose partner had only a TBI with no comorbid PTSD was the one person who despite a rough initial transition following the veteran’s TBI appeared to experience the least day-to-day distress. She spoke of financial concerns and worries, but did not reference the worry, stress, sadness, distress, and frustration that the others expressed. This suggests that the concurrent presence of TBI and PTSD symptoms contributes to an overall sense of distress that may not be present for women whose veteran partner is healing from “just” a TBI. Currently, there is ongoing scientific exploration of the recovery trajectory for military service personnel who have both a TBI and PTSD. The preliminary findings suggesting that the presence of one inhibits the anticipated recovery path of the other. This will continue to be an important area of focus for structuring care for veterans, but also for creating appropriate support for their intimate partners.

Health related quality of life. A longitudinal study assessing the health related quality of life of caregivers of service members with TBIs has been funded by the Defense and Veterans Brain Injury Center (DVBIC). The study is currently in the beginning stages with a 2015 target date for completion of the research (DVBIC, 2011). It will be extraordinarily interesting to follow the research to see if it affirms the findings of this study; spouses acting as caregivers for veterans with TBIs describe lives of unpredictable stress and distress which ultimately takes a

toll on the physical and emotional well-being of the spouses. As noted earlier, three of the women reported “break downs” while others described significant challenges related to their overall wellbeing which at its most basic level consists of more positive life experiences than negative ones. One participant described a “chewing out” she received from her primary care physician as both her weight and blood pressure were up since her husband returned home from his deployment with PTSD and a TBI. Another woman talked of her excessive weight gain, inability to sleep, and difficulty processing her own emotions. Personal health related quality of life issues were not topics the women discussed in length, but they grazed the subject enough to indicate that caring for their veteran spouses was taking a toll on their own wellbeing.

Caregiving. When this research began, I was not yet convinced that “caregiver” was an appropriate term to use when referencing the partners of veterans with at TBI. The research on military families did not consistently use the term when discussing partners of those with neuro-cognitive injuries and when the term appeared, it did so without clear definition. At this juncture in time, caregiver does seem to be an appropriate term to use when discussing the women in this study. All of them referenced caregiving activities and shouldered a caregiving burden of some sort. As discussed earlier, caregiving burden may viewed as the degree to which the emotional, financial, social, physical aspects of the veterans’ partners lives have been negatively impacted by the provision of care to their loved one (Dekel, Solomon, & Bleich, 2005).

In this study, the partners expressed what can best be described as an obligation to take care of their injured veteran husbands. The care was divided into two distinct areas; objective work such as paying bills, making doctor’s appointments and subjective work which was more the worry, strain, and stress associated with the caregiving itself. Added to the mix was the disruption of the “known” relationship as the women worked to relearn who their husbands were

post injury. The PTSD and TBI symptoms of irritability, difficulty processing and regulating emotions, and lack of emotional availability were all critical to the caregiving relationships the women had with their husbands. The women's ability to "see the man they once knew" influenced their caregiving burden as they could then reframe the experience as tending to the needs of a loved one as opposed to caring for a strange man so unlike the person they married.

The women's commitment to their relationships grew from a vast complex of cognitive and emotional sources unique to each individual participant. Their expressed love for their husbands was a critical source of balance for the subjective caregiving burden they shouldered. I found this to be similar to what Swedish nurse researchers found when studying family members of civilians with TBIs; families sought to balance their own sense of suffering while reaching out to the injured individual with a compassion based in an ethical need to be present and a feeling of love for the family member (Jumisko, Lexell, & Söderberg, 2007). The caregivers I interviewed described a love for the man they married; not always the man present in their lives today, but every now and then, they were able to "see" the person they loved which was affirmation enough for them to continue on the path as caregiver.

Public Law 111-163, Caregivers and Veterans Omnibus Health Services Act of 2010, authorized monetary stipends for primary caregivers of post 9/11 veterans (United States Department of Veterans Affairs, 2011b). In May of 2011 the program opened to receive applications from family members caring for seriously wounded veterans and received 1,119 applications within the first thirty days (Miles, 2011). There are a number of very specific eligibility requirements for the program including the stipulation that without the ongoing support of the caregiver, the veteran would require institutional care, hospitalization, or nursing home care (Implementation of Caregiver, 2011). The average monthly stipend paid to caregivers

is \$1600 (Krooks, 2011) which is significantly below the market cost of full time caregiver services. In Southeastern urban areas home health aides working 40 hours a week, make on average, \$1917 a month (Indeed, 2012). The caregiving services provided by the partners in this study range far beyond a forty hour work week and basic assistance with activities of daily living (ADL). A conservative calculated estimate for the cost of weekly in home ADL assistance including evenings and weekends is in the range of \$4,000 a month. This does not include additional necessary services such as the provision of transportation to medical appointments, grocery shopping and meal preparation, assistance with the completion of necessary paperwork for VA benefits, nor support for career counseling and retraining. As noted in testimony presented to the Joint Economic Committee (Eibner, 2008) microsimulation models designed to predict the two year post-deployment costs for veterans with TBIs suggest that the one year cost for those with a TBI is between \$591 to \$910 million dollars. This figure does not include the far ranging societal costs such as caregiver burden, homelessness, and substance abuse. Nor does the figure include any costs for military service personnel with mild TBIs or those who have not received a definitive diagnosis of a TBI.

While extraordinarily difficult to calculate the precise financial impact of partners functioning as veteran caregivers, the consequences of their absence is not difficult to predict. Models formulated to frame veterans' post combat mental health and neurocognitive conditions (Tanielian & Jaycox, 2008) include divorce, crime, homelessness, suicide, unemployment, health compromising behaviors, and poor parenting skills. The cost of VA homeless programs and services alone is \$939 million a year (White House, 2012). The VA and DoD estimate that on any given night, there are 67,000 homeless veterans on the streets in the United states (National Coalition for Homeless Veterans, 2012). The strongest predictive factor of homelessness in the

veteran population is substance abuse and the most significant protective factor is a veteran service connected disability rating greater than 50% (Edens, Kaspro, Tsai, & Rosenheck, 2011). Among veterans who served in the wars in Iraq and Afghanistan, those with severe mental illness such as schizophrenia or bipolar disorder have a significantly higher risk of homelessness surpassed only by veteran substance abusers whose risk is four fold that of the general population under discussion (Edens et al., 2011). The presence of committed partners assuming caretaking responsibilities for veterans with neurocognitive injuries does not eliminate the possibility that the veteran will become a substance abuser or end up homeless, but an argument could certainly be made that the 24/7, comprehensive, 1:1 home care provided by partners does significantly reduce the risk and thus, the overall financial costs to society.

Intimate partner violence. The risk of intimate partner violence (IPV) rises in subsets of the population where an individual in the domestic partnership experiences loss of impulse control, one of the hallmarks of TBI (Tanielian & Jaycox, 2008). In this sample there are multiple areas of risk as it relates to the potential for IPV. The link between veterans with a diagnosis of PTSD and the significant increase in the risk for IPV has been repeatedly demonstrated (Elbogen et al., 2010). None of the women who participated in this study reported or referenced any physical violence on the part of their husbands. There were discussions of what could easily be categorized as emotional and verbal abuse perpetrated by their husbands. Whether it was the effects of lingering PTSD or TBI symptoms increasing the likelihood of perpetrating abuse is really irrelevant for the purposes of this discussion. What is critically important is imparting a skill set which allows the women to protect themselves. This may range from teaching skills aimed to deescalate scenarios involving charged emotional interchanges or giving more practical advice regarding where to stash extra car keys should the women feel as if

they need to make an immediate departure from the situation. The hyperarousal symptoms associated with PTSD dictate that every woman partnered to a veteran with PTSD have a rudimentary understanding of her own personal safety choices.

The one potential study participant whose veteran husband prohibited her from meeting with me is a stark illustration of the fear, isolation, and potential danger some of the spouses live with on a daily basis. She was hesitant to return calls on her own personal cell phone, feared meeting anyone at her home, and ultimately chose to abide by her husband's demands as she was afraid to do anything that might further upset him. Another woman who did meet for an interview assured me that her husband knew she was talking with me and had no concerns related to the same. However, she repeatedly lied to him when he called on her cell phone during the interview. Stating she was at the pediatricians with their child, she maintained the lie in a conversation lasting at least 15 minutes, bolstering her falsehood of where she was and what she was doing by covering the mouth piece of the cell phone when outside noises would indicate that she was not in a doctor's office. I have no way of knowing if this behavior was based on her fears of his response or if dishonesty has always been par for the course in their relationship. There is no doubt that the link between deployment, PTSD, TBI, and IPV is one of complex factors, but the fact remains; every woman needs to have a basic safety plan.

Opportunities for interventions. It would be remiss to have noted and cataloged all the challenges faced by the partners of veterans and specifically the women in this study, without providing possibilities for addressing some of those same challenges. The framework for focusing on the multitude of interwoven needs for support and education could conceivably be constricted to fit under the umbrella of nursing practice. However, believing the needs of veteran

partners span a wider range of opportunities for support and care I have opted to include a general summary at this point in the discussion.

Six of the seven women in this study lived through their husband's deployments to Iraq. Many of them developed a previously untapped source of strength in making it through that experience; they took on new roles which allowed them to keep the household running, managed their anxiety and fears regarding the safety of their husbands, and were able to access support specifically designed for partners of military service personnel in combat areas. All six mentioned some small piece of that experience in the interview process. As many noted, they had already developed a strong sense of strength and resiliency prior to current day life, discussing the transition from active duty to veteran status as yet another step in the process of growing into the women they are today.

The skills this group of women acquired as a "military spouse" allowed them to reach out for help in the community as all of the participants came to the study through a community gatekeeper, a community provider. The incredible number of services and programs addressing behavioral health and TBIs in military service personnel can be a barrier rather than an opening for accessing care. At last count, there were over 211 programs providing active services and interventions specific to meet the needs of the sample (Weinick et al., 2011). Trying to determine which program is appropriate to each family is a herculean task best undertaken by someone with a familiarity with the systems in place. Unfortunately, there is no one central source that has knowledge regarding the various programs, nor are programs integrated into existing systems of care. The programs themselves offer services ranging from psycho-education for specific injuries over a continuum of time to peer-to-peer online support groups to response units specific for IPV in the target population.

The participants in this study could have benefitted from some very focused psycho-education, support, and access to mental health care early on in their husband's recovery process. Their descriptions of trying to understand what a TBI was, how to fill out "mountains" of paperwork to apply for health benefits, and where to go for specialized care was difficult to hear given the fact that they were caring for one who was injured in combat, in service to our country. However, even with the passing of time, the majority of them could still benefit from continued support be it couples counseling, information on communication skills, access to respite programs for themselves, peer support, computer mediated communication with specialty mental health care providers, or further guidance on reintegration dynamics two years down the road.

The method for accessing necessary support and care remains erratic and elusive for most. It would be most efficacious if there were one central location, accessible by telephone, which could direct individual inquires to experts on regional programs and resources. As it currently stands the programs are fractured, spread out between the Department of Defense and civilian arenas with breakdown in communications beginning at the branches of service levels and extending onward from that point forward into the military and civilian worlds (Weinick et al., 2011). Appropriate service and program identification is just the initial starting point. There are additional needs regarding program evaluations on effectiveness and possible duplications. As one participant put it, however well-intentioned it all is, it remains, "a colossal mess."

Synopsis of research findings. The findings of this phenomenological study resonate with the findings from research regarding TBI caregiving in the civilian population, neurocognitive injuries of military service personnel and its impact on spouses, and the transition for couples going from deployment to post-deployment. The themes of "Change and Difference," "Making Sense of the World," "Redefinition of Self," "Alone," and "Commitment

and Perseverance” all find purchase in the three areas of research mentioned. Not all five themes are found in all three areas, but there is most certainly overlap such that the TBI literature speaks to change, as do the writings on deployment/post-deployment challenges. The participants’ struggle with trying to understand a new world, post neurocognitive injury has similarities with the civilian TBI literature and the military PTSD literature. Redefinition of self is a task undertaken at the deployment/post-deployment juncture and when civilian and military couples strive to adjust to neurocognitive injuries. Feeling alone and needing support from a variety of sources was specifically identified as a theme in a phenomenological nursing study conducted on the transition of persons as they became the informal caregiver for a family member (Pereira & Botelho, 2011). The civilian TBI literature speaks to the impact of social and family support on the well-being of the caregiver, contrasting it to feels of isolation and feeling alone (Rotondi, Sinkule, & Spring, 2005). As noted in the veteran PTSD and TBI literature, the role of stigma is not to be underestimated in the caregivers’ withdrawal from social support. Finally, the task of caring for a partner with a TBI is one undertaken with leverage provided by a concept as simple as the love one individual has for another. The ability to persevere in light of extreme difficulties is not an aberrant factor when commitment is based on marital vows, pledges of “in sickness and in health,” or in the intimacy that propagates over years spent together as a couple.

What makes this study unusual is the intertwining of all five themes throughout one sample, one group of participants who share a trio of factors; caregiving a partner with a TBI, post-deployment adjustments, and a history of military service in light of the neurocognitive injury. One may be tempted to say that the participants’ magnified the themes, concepts, and conclusions found throughout the literature previously mentioned. They were, by and large, a committed group of women who were devoted to their veteran partners. The struggle to adjust

and readjust to the perpetual change and “not knowing” left them employing new coping skills as they sought to understand how to navigate their “new normal.”

Implications for Nursing

This study’s implications for nursing practice, research, education, and policy are significant. The findings build upon a now growing body of literature focused on how to best care for the families of veterans with neurocognitive injuries as well as for the veterans themselves. Nurses already are, and will continue to be encountering veterans and their families across a wide swath of non-military, non-veteran health care settings ranging from primary care clinics in a rural setting to busy emergency departments in urban areas. The population of individuals impacted by veterans’ neurocognitive injuries from the wars in Iraq and Afghanistan will be just as likely to be seeking care from pediatric nurse practitioners and demanding policy changes from nurses who are instrumental in the formation of national health policy.

Practice. There a multitude of entry points for the application of this study’s findings in the realm of nursing practice. Women in this research did not only seek care for themselves, their partners and their children at VA centers. Instead, they visited private practitioners and therapists within the civilian community. Therefore, first and foremost is the necessity to include in every assessment routine questions regarding a family’s history with the military. Nurses have the opportunity to enhance the provision of nursing care to families if they address military history in their initial clinical interview across a range of settings such as pediatrics, obstetrics and/or gynecology, mental health, primary care, emergency departments, internal medicine, and public health clinics. The need to screen for developing signs and symptoms of stress and distress in the caregivers of veterans with TBIs will be critical to the provision of appropriate nursing care

designed to support caregivers. This type of care is predicated on nurses obtaining a clear picture of the family's military history.

As nurses, we are incumbent to not only listen to our patients, but to actually hear what they are saying which entails more than simply asking one question about the family's military experiences. Women in this research were reluctant to initiate discussion of their families' problems with people who did not express non-judgmental caring interest. Therefore it is incumbent on nurses in practice to take the first step to inquire about military history, presence of TBI, and the family stressors that accompany it. For example, over 50% of children whose parents are active duty military receive their care outside of the military system (Davis, Blaschke, & Stafford, 2012) and once separated from the military, all children of former military service personnel receive their care in the community. Nurses in pediatric settings work with parents as well as children. If an initial pediatric assessment highlights a family system inclusive of a veteran struggling with the neurocognitive sequelae from combat, nurses can initiate suitable referrals for all family members. The time spent in assessment and history taking may reveal a family system in need of support, but nurses will need to use their expertise and skills in fleshing out the difference between a child's routine stomach ache related to the "virus of the week" and a child's stomach ache in response to having their veteran parent at home with significant mental health issues. Nurses need to skillfully engage with patients and their families so as to promote trust and facilitate the patients' communication of thoughts and experiences. Only then can nurses respond to the complex needs of patients, structuring care and enhancing health seeking behaviors.

The 2003 U.S. Census data showed that the large majority of veterans and their families live outside of urban areas, in rural communities frequently far removed from VA medical

centers and their expertise regarding the long ranging impacts of combat acquired neurocognitive injuries (Straits-Tröster et al., 2011). In rural settings, health care providers may not be as aware of the challenge of diagnosing combat acquired TBIs and totally unaware of the impact such has on partners and spouses (Tanielian & Jaycox, 2008). Nurses are frequently on the front lines when it comes to the provision of care in rural areas as nurses can be found in schools, rural health care clinics, and correctional facilities. They are in a unique position to reach out to rural community stakeholders such as educators, clergy members, and criminal justice personnel all of whom are most likely to be the first point of contact for veterans experiencing mental and behavioral health issues related to their time in combat (Kirchner, Farmer, Shue, Blevins, & Sullivan, 2011).

Nurses working with or in the VA system may extend their current systems of care to include basic psychological support and education for all partners of veterans with TBIs. The civilian brain injury literature supports the advancement of educational information as a means to decrease stress and increase coping in family members of individuals with TBIs (Kreutzer, Stejskal, Godwin, Powell, & Arango-Lasprilla, 2010; Morris, 2001; Sinnakaruppan, Downey, & Morrison, 2005). Existing VA and Department of Defense educational materials aimed at care providers of military service personnel such as *The TBI Family Caregiver Curriculum* are easily accessible on line (DVBIC, 2010). It is the responsibility of all health care providers, including nurses, who work with veterans and their families to direct them to the wealth of educational and informational materials freely available at no charge. In addition to targeting the problem focused coping efforts of families through the provision of appropriate interventions, multiple opportunities exist for nurses to enhance the emotion focused coping skills of veterans and their families. The current literature contains a number of possible approaches to support emotion

focused coping; these range from normalizing the emotional responses (Bowling & Sherman, 2008) to communication and problem solving skills training (Dekel & Monson, 2010) such that partners of veterans learn the tools to reframe and protect themselves from the potential ongoing emotional trauma. Of note, there is a paucity of research on the effectiveness of coping interventions designed to meet the needs of this population.

Research. Nurse researchers Pereira and Botelho (2011) examined how nurses can facilitate an individual's sudden transition to the role of informal caregiver. They concluded that it is essential for nurses to participate in the development of interventions related to the experience of becoming a caregiver. The researchers suggested the use of Meleis's middle-range theory of "Experiencing Transitions" (Meleis, Sawyer, Im, Messias, & Schumacher, 2000) as a framework to begin the nursing process. There are a number of other nursing theories which lend themselves to further theory based nursing research with this sample. For example, Tsai's middle-range theory of caregiver stress (2003), an adaptation of Roy's adaption model, predicts caregiver stress from a number of variables. Additionally, nurse researchers would do well to engage the theory of ambiguous loss for further study on veterans' families learning how to adapt and cope with the veterans' TBI as the theory has been used to frame research conducted in the clinical TBI community and as well as in the military community.

The use of the classic Lazarus and Folkman (1984) stress, appraisal and coping theory as well as its subsequent renditions of the same over the years would be beneficial to those nurse researchers who seek to locate the points where the partners of veterans can begin to increase their abilities to cope with a challenging and stressful caregiving environment. Studies designed to evaluate the use of coping effectiveness training as offered at various points in the longitudinal recovery and reintegration process could potentially be extraordinarily beneficial in promoting

optimal health and reducing psychological distress. There are no doubt a multitude of additional nursing theories which could be a good fit for the study of caregivers of veterans with TBIs.

Education. In the ten years between September of 2001 and September of 2011 over two million military service personal have been deployed to Iraq and Afghanistan (Taylor et al., 2012). Currently, close to 55 percent of those in the military are married and over 40 percent have at least two children (Department of Defense, 2011). Of those military families, close to 63 percent live off base in communities all over the country (Flake, Davis, Johnson, & Middleton, 2009). Those statistics alone are reason enough to address the basic features of the military service in entry level nursing education programs as nurses will be encountering active duty personnel, veterans, and their families in every imaginable health care setting. Add to that the current practice of multiple deployments over a military career, the complexity of combat injuries, and the challenges facing military and veteran families and one could easily make a case for expanding nursing education to include a much more comprehensive understanding of the unique needs of those coming from military or veteran families.

One need only peripherally follow the national news to gain an understanding regarding the dearth of qualified individuals in our nation's health care systems that are prepared to meet the mental health needs of combat veterans from Iraq and Afghanistan (Dao, 2012). At this juncture, it is imperative for nursing education to take the lead and begin to address the gap in clinical providers by designing distinct programs of clinical training focused on the provision of care to service members and their families.

The post 9/11 GI Bill provides for education and housing financial support for veterans if they choose to pursue additional education. The Yellow Ribbon program augments these funds such that veterans may enroll at private colleges and universities with discounted tuition and

fees. Not all families are aware of the fact that service members can transfer unused post 9/11 GI bill education funds to their spouses or children. The partners of veterans with neurocognitive injuries have a unique set of challenges upon return to an academic setting. Many, if not most, institutions of higher education have a specific individual responsible for addressing the educational needs of veterans. A select few academic institutions have developed an entire programming office directed to provide support to veterans and their families as they seek college degrees. These veteran support offices are frequently an available resource for the partners of veterans, even if they are not students. Over 2 million individuals are eligible to receive the post 9/11 GI Bill educational funds meaning veterans and their family members will likely have a presence in the majority of our higher education settings. Nurse educators need to develop a basic understanding of the unique needs of this population and make appropriate accommodations when necessary. There are a number of regional half-day programs which rotate to various institutions of higher learning. These programs target academic professionals and are aimed at providing an overview of the specific classroom and learning needs of veterans and their families.

Policy. Congressional hearings on the needs of service members with TBIs and their caregivers contributed to the portion of The National Defense Authorization Act of 2007 which included the creation of a panel of health care experts to develop a training curriculum for family caregivers of service members with TBIs: *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*. (DVBIC, 2010). There is not a parallel curriculum for caregivers of service members and veterans with PTSD (M. Wilmore, personal communication, April 10, 2012), but one would certainly be beneficial to the participants of this study who are to some degree, representative of the hundreds of thousands of those who are partnered with veterans

with TBI and PTSD or just PTSD. The funding for such comprehensive training guides in hard copy and available online, must come from the federal government. As nurses and as citizens, I feel that we have the responsibility to keep the needs of those who served our country in the forefront of the local, state, and national agendas. Irrespective of political beliefs, as nurses who are involved in the provision of quality care to veterans with neurocognitive injuries and their families, we must have access to resources to enhance their ongoing care. This comes in the form of funds to establish adequate “slots” in PTSD treatment programs for veterans as well as funds to support the VA Caregiver Program, to name a few.

A number of partners and families of veterans with TBIs have called their congressional representatives, organized on Facebook, and spoken at congressional hearings on the challenges they encountered in enrolling in the VA Caregivers Assistance program (*Implementation of Caregiver*, 2011), but there are undoubtedly additional opportunities for partners to organize and impact policy change. The Wounded Warrior Project, a non-profit organization whose mission is to honor and empower wounded veterans, has a team whose sole purpose is creating and lobbying for legislation to enhance the quality of life for wounded veterans and their families. The possibilities to become involved in the process of advocating for change exist, but partners of wounded veterans may find it challenging to find the time and energy to locate the specific groups that highlight their needs. Additionally, this research study highlights the day-to-day demands on the time and energy of partners of veterans with TBIs. Theoretically, the partners of wounded veterans could mobilize to promote policy changes, but their current realities appear to offer limited time to organize and pursue political agendas which advance their cause.

The position of nursing as an entity to influence the ongoing development of quality care, programming, research, and policy aimed at supporting military and veteran families is not a

burden to endure, but an opportunity to explore. Speaking up and out for marginalized vulnerable populations is critical to the task of delivering the best nursing care possible something the majority of nurses are proud to be a part of.

Strengths and Limitations of Study

Strengths. The strength of this study revolves around the unique characteristics of the study participants. They have a combination of personal and demographic characteristics which are shared by many partners of veteran, but not studied and described as a subset of the sample; those partnered to a veteran who sustained a TBI while deployed in the military and currently living as a civilian post-deployment experience. The sheer number of those married to veterans with both TBI and PTSD ensure that this sample will be in need of attention in the future. When it is important to gain a better understanding of the shared experiences of a group of individuals a phenomenological approach proves to be a good fit for developing a comprehensive description of the experience (Creswell, 2007). The use of the social constructivist lens to approach this research topic lent yet another tool with which to begin to understand the meaning persons ascribed to their lives as they themselves live it within their unique personal, social, cultural, and historical experiences.

Limitations. The description of the participants' experiences rang true to those participants who had previously indicated a willingness to review the collective themes from the narratives. In that sense, the findings remain valid, reliable, and generalizable to the participants in this specific study. Those who chose to participate in the study had already accessed care outside of the VA system utilizing expert providers in their communities as well as the using the services of the Army Wounded Warrior or similar programs. They were a group of "well

connected” women. Missing are those participants who are alienated from all systems of support and care.

All in the study were women, all married, and heterosexual. It would have been beneficial to have had diversity outside of race for a broader picture of the lived experiences of the sample. Additionally, the sample for this study was generally homogenous which constricted the range of participants’ perceptions and experiences. A more diverse sample including those who were struggling to cope, were questioning their willingness to stay in the committed relationship, and who had constructed vastly different avenues of support would have enriched the findings of the study. Their absence is a significant limitation.

All but one of the participants was married to a veteran with both TBI and PTSD which makes the findings quite specific to this cross-section of individuals. There were distinct differences between those partners living with veterans with both PTSD and a TBI and the one woman whose veteran husband had a TBI with no comorbid PTSD. It is doubtful that the disparities in the lived experiences can be solely attributed to individual personal and family characteristics. Much more likely is the possibility that the comorbid presence of TBI and PTSD impacts the lived experience in a profound manner. The challenges in participant recruitment led those who may have wanted to participate choose not to, for fear of their veteran partners’ reaction to their talking with an unknown “outsider.” The restraints the participants had on availability of time they had to meet with the researcher may have been a factor in what they chose to describe. A few of the interviews were “rushed” as there was a pre-determined deadline to finish the interview process.

Future Research

Future research should be focused on any one of a multiplicity of aspects related to the experiences of partners of veterans with neurocognitive injuries. Possible research questions are listed as follows:

- What motivates partners of veterans to participate in research studies?
- What do the partners experience as caregiving challenges, in what part of the longitudinal caregiving process?
- What types of support have proven to be helpful in their overall quality of life?
- What types of information and education are the most helpful (printed materials, internet resources, “live person” available by telephone, informational groups, etc.) in addressing their stated needs? When should this information be offered (immediately, transition from military to civilian, six months after the transition, annually, etc.)?
- What are the barriers to partners’ being able to access the resources available to them?
- Does the Defense and Veterans Brain Injury Center’s online curriculum, *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans* designed to inform and “reduce the stress of caregivers” actually do so?
- What type of collaboration can be most effective in meeting the needs of partners of veterans with TBIs and PTSD?
- Do the needs of the partners change over the years? If so, how do they change?
- What is the lived experience of the partners of veterans with TBIs ten years post injury?

Future research to include the experiences of both veterans with TBIs and their partners as part of the same study would be valuable in elucidating the unique needs of these couples. The literature contains a large number of research studies on veterans with combat acquired PTSD and its impact on their partners, but there remains a need for further research with partners of those who have only combat acquired TBIs and not comorbid PTSD. Additional research on the experience of partners of combat veterans with TBIs with the inclusion of a control group of partners of veterans with no combat acquired injuries would lend a more comprehensive understanding of the components which comprise the experience as a whole; transition from military to civilian, reintegration, role shifts, and all the facets of caregiving.

The complex set of challenges presented by this population necessitates an equally complex set of assessments and interventions designed to address their most pressing concerns. For example, would it be beneficial to construct an integrated holistic system of care aimed at meeting the needs of the entire family or should the treatment be prioritized to address more pressing singular issues such as intimate partner violence, the well-being of the partners, or the process of obtaining appropriate mental health care for the veterans? Another area in need of focused research efforts is that of potential interventions to support both partners' emotion focused and problem focused coping. What has worked in the civilian population that could be modified to serve the needs of veterans or what strategies have been used to enhance the coping skills of veterans with chronic conditions? Researchers explored coping effectiveness training (CET) provided to a sample of veterans with spinal cord injuries during their acute rehabilitation phases, contrasting it with a group receiving supportive group therapy (Duchnick, Letsch, & Curtiss, 2009). They found that both approaches had an impact on the depression and anxiety of veterans at discharge with no statically significant difference between the two modalities. Similar

research designed to determine what is most effective in supporting the coping and adjustment of the partners of veterans over a continuum of time would no doubt lead to more appropriately targeted interventions.

Recruitment challenges have been discussed earlier, but the difficulties are worth highlighting in this discussion of future research. As noted, nearly 50% of former military service personnel receive their health care through the VA. In hindsight, the opportunity to return to this study's participants for follow-up interviews would be very beneficial to the construction of a deeper understanding of their experiences. I have come to realize how pivotal trust is when discussing emotionally sensitive topics such as the participants' own difficulties with their mental health. If I had known this at the start, I could have added a question about the participant's willingness to participate in an additional interview and sought consent for the same. Three of the participants referenced a "breakdown" in some form or fashion, but as mentioned earlier, I did not actively pursue further descriptions of such as the participants' seemed to be quite guarded at that point in the interviews. It would have been much more appropriate to seek elaboration on the sensitive topics at a second interview when I was "known" to the participants.

The drawdown of combat troops from Iraq was completed in December of 2011 and the combat role of the US in Afghanistan is shrinking with a projected closure anticipated sometime in 2014 (Rhodes, 2011). The needs of veterans and their families will not end when the wars come to a close. Continued research will allow nurses to provide the best care to military families as the years progress.

Given that combat acquired blast induced TBIs are just now beginning to be appreciated on the cellular level, the long term sequelae are simply unknown. It remains critically important

for civilian and military persons to collaborate as they follow families of veterans with TBIs and PTSD such that their needs can be determined, interventions for support can be crafted, and their quality of life improved. As a parallel to such, research should continue to evaluate the effectiveness of support measures and targeted interventions.

Summary

This dissertation described the experiences of partners of veterans with TBIs acquired during their time serving in the war efforts in Iraq. Study recruitment posed unanticipated, but understandable challenges. All of the seven participants were women, married to their veteran partner who had a TBI. 85% of the veterans had both a TBI and PTSD, generally reflective of the national sample of military personnel with TBIs.

There were distinct similarities to the rich narratives provided by the women in face-to-face interviews with the research. The five identified themes emerged on a back drop of the contextual ground of “Shifting Sands.” The themes were: “*The Person I Married is Not the Person I See*”: Change and Difference, “*They Just Don’t Understand*”: Making Sense of the World, “*It Transforms All of You*”: Redefinition of Self, “*I’m on an Island By Myself*”: Alone, and “*I Won’t Give Up on Him, Ever*”: Commitment and Perseverance. The majority of participants spoke of their desires to learn more about their husbands’ injuries. As a group, they felt unprepared for the transition from military to civilian life with a husband with neurocognitive injuries from the war. Three of the seven of them cynically stated that their send off from the military was one under scored with a “Good luck with that [husband]” and no further direction on how to care for the man who had changed so radically from the man they married.

The knowledge gained from this study serves to give expression to those whose voices may be marginalized in the context of war; the voices of veteran partners. This qualitative study broadly adds to the research literature on the experience of caregivers to those with TBIs and specifically, to the small but growing body of literature on the partners of veterans with TBIs and PTSD.

Personal Reflections

The process of constructing this phenomenological research study opened my eyes to the extensive community resources available to our nation's veterans, but also to the difficulty in accessing those resources. Additionally, the experience highlighted the huge gaps in knowledge regarding the needs of veteran spouses and the subsequent lack of services aimed at supporting those spouses. The opportunity to meet with the veterans' partners and hear their stories was both exhilarating and terribly frustrating. It brought to mind the daily challenges I experienced when working within the VA system; a system designed to deliver health care focused on the needs of veterans, but overwhelmed by both the complexity and quantity of needs.

After the first interview, I returned home telling my spouse, "It was just like going to work," referencing the years spent employed by the VA Medical Center. Then, as now, I felt waves of righteous indignation regarding the lack of focused support for former military personnel and their families. This was generally accompanied by a sense of gratitude for those individuals within the system who saw a need, reached out, and tried to fill that need. While only two of the seven participants spoke in an outright disparagingly manner regarding the difficulty in navigating the VA health care system, I was bitterly dismayed that they had encountered frequent dead-ends and health care providers who were seemingly unable to see the person behind the number or need. I did track down additional community resource options for two of

the participants, but sometimes found myself at the same dead ends they themselves described. It left me wishing I was still working in the VA system such that I could more easily access and manipulate the tools necessary to locate resources. At the end of the interview process I found myself “missing” the contacts with the veteran world. As always, I have the utmost respect and admiration for those who support those who serve.

In the end, I felt as if I carried through with a promise made to many of the partners of veterans when I left the VA system in late 2009. I assured them that they would not be forgotten, that I would do my best to “do something” to give voice to their experiences. The completion of this research is just that, giving voice to the lived experiences of the partners of veterans with TBIs. I am proud of the work I have done, but even more than that I find myself in awe of the men and women who support those who have served.

All efforts, across all possible settings, should continue to work to promote peace between nations such that studies such as this became unnecessary. Until that time, we must continue to educate clinicians and pursue research based on the needs of our country’s veteran population. We are obligated to provide quality comprehensive care for those who have sustained harm while caught up in the conflicts of institutions, nation states, and powers which far exceed their own personal control. If anything, hearing the clear distinct voices of the women in this study has reinforced my beliefs that institutional violence does not solve the problems of nations, it simply perpetuates a different sort of violence; that against our shared humanity.

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Appendix A

Informed Consent Form

Introduction

You are invited to participate in this research study because you are the legal spouse or the domestic partner of an Iraq or Afghan combat veteran with a traumatic brain injury. This study is trying to understand what it is like to live with a veteran with a TBI, to understand your experiences of caring for our country's wounded warriors. This study is being conducted by Laurel Cassidy who is a doctoral student at the College of Nursing at the University of Tennessee Knoxville (UTK) in the global disaster nursing program and who has 20 years of experience working with families under stress.

Information about participant's involvement in the study (What is expected of you)

If you agree to participate, you will be asked to complete a questionnaire with basic information about you and take part in a private interview with the researcher, Laurel Cassidy. The questionnaire will take about ten minutes to complete and the interview will last approximately 60 to 90 minutes. However it may be longer or shorter depending on what works for you. The interview will be over when you say it is over. The interview will consist of your describing your experience of life with your veteran partner. The interview will be recorded on a digital recording device. All information you provide will be kept confidential. The files will be stored as MP3 files on the researcher's password protected computer until they can be transcribed. Once they are transcribed by a professional transcriptionist, who will have signed a confidentiality agreement, the files will be put on a USB flash drive and taken to UTK by Ms. Cassidy where the drive will be stored for three years in a locked cabinet in the office of Ms. Cassidy's academic advisor. The names of all the people and places will be changed on the written transcripts to protect your identity. Only the researcher will know what written names go with which individual. The signed consent forms, written transcripts, and UBS flash drive with the digital files will be kept in locked files in separate places with no connection between them. No written materials will have any information that could possibly identify any one individual. You will be asked if you would like a summary of the study findings which will be available after the research is complete. You will be asked to sign on a separate line if you want the results. You will be asked for your contact information to get the summary to you. If during the course of the interview you tell Ms. Cassidy about an immediate danger to self or others or of a potential significant risk of harm to a child, an elderly person, or a disabled person, she is legally and ethically obligated to file a report with the appropriate state agency

Risks

There are possible risks to you from participating in the study. You might feel uncomfortable, anxious, or sad when discussing your needs. We can pause or take a break and if you would like, we can end the interview. A list of available resources for family members of veterans with TBI will be given to you after the interview. There is also a risk of loss of confidentiality. To minimize this risk, we will be meeting in a private place. The only people who will hear or see what you describe will be Ms. Cassidy, her faculty advisor Dr. Speraw, the transcriptionist, and the research group at UTK. Dr. Speraw has worked with many doctoral students doing confidential interviews. The transcriptionist and research group sign a confidentiality agreement saying they will not discuss this with anyone. The only certain breach of your confidentiality will be if you describe an immediate risk of harm to yourself or others as by law that will have to be reported.

Initial_____

Benefits

The benefit of this study is the opportunity to describe your experience of living with a veteran with a TBI. Your description of your experience will add to the knowledge of what the experience is like such that health professionals may better understand how to assist in supporting veteran partners such as yourself. Very often it is helpful to talk to someone who wants to hear your story and who understands, but there is the risk that you may become upset. You will receive a \$25.00 Walmart gift card as an incentive for participating in this study. You may choose to withdraw from the study at any time without returning the gift card.

Questions

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,) you may contact the researcher, Laurel Cassidy, lcassid1@utk.edu or 615-***-****. If you have questions about your rights as a participant, contact the UT Office of Research Compliance Officer, Brenda Lawson, email address blawson@utk.edu, telephone (865) 974-3466, or write to her at 1534 White Ave., University of Tennessee Knoxville, Compliance Section of the Office of Research, Knoxville, TN, 37996-1529.

Participation

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time. Withdrawing will not affect you or your veteran partner's access to any care or any benefits. If you withdraw from the study before data collection is completed your data be used up to the point that it has been collected or if you would like, I will erase the file in your presence. Your participation will not impact your veteran partner's benefits or eligibility for service in any way.

CONSENT

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

I would like to receive a summary of the study findings.

Participant's signature _____ Date _____

Please send it to me at this address:

Appendix B

Sample Follow-up Questions for Interview

- Would you tell me a little more about that?
- I am not exactly clear on _____, could you say more?
- Could you give me an example of what you are describing?
- Would you share how _____ was for you?
- Would you say more about the specifics of how your life has or has not changed since your partner returned?

Appendix C Demographic Questionnaire

Please circle the answer that best describes **You**:

Gender

- Male
- Female

Age

- Under 20
- 21-29
- 30-39
- 40-49
- Over 50

Employment

- Full time
- Part-time
- None

Number of years you and veteran have been living together

- 2 years
- 2-4 years
- 5-10 years
- 10 or more years

Number of children living in your home

- 0
- 1
- 2
- 3
- 4
- 5 or more

Veteran Partner

Gender

- Male
- Female

Age

- Under 20
- 21-29
- 30-39
- 40-49
- Over 50

Number of Deployments

- Afghanistan _____
- Iraq _____

Injuries/Medical Conditions

- Traumatic Brain Injury (date) _____

Type of TBI (if known)

- Mild _____ Moderate _____
- Severe _____

Additional injuries or medical conditions of veteran

- _____
- _____
- _____

Where does your veteran partner receive health care services? (circle)

- VA Hospital or Clinic
- Private Health Care Provide

Appendix D

Did your Iraq or Afghan veteran spouse or partner receive a TBI during their deployment? Was it two or more years ago?

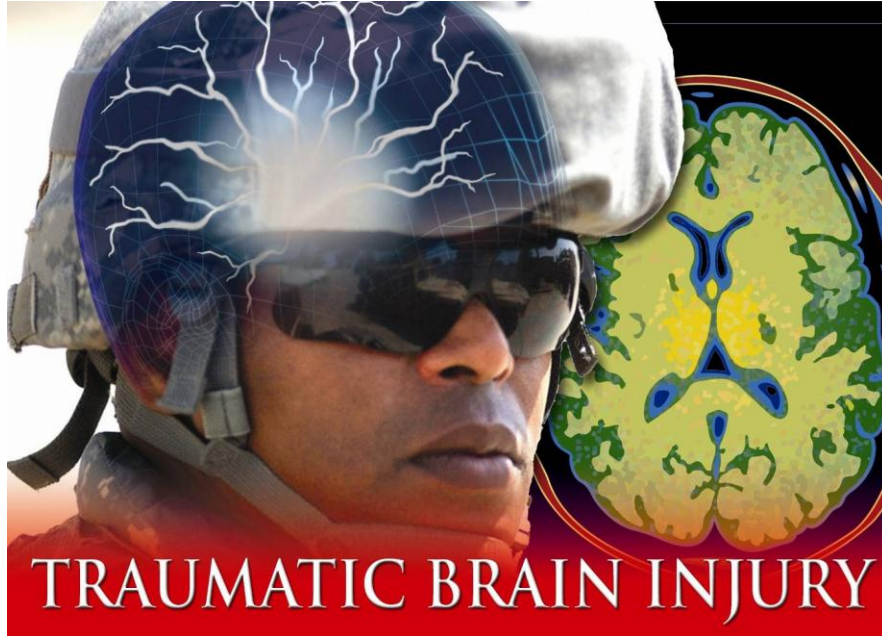


Photo by Matt Staley (public domain)

What: A nursing research study seeking to understand and describe what it is like to live with a veteran who received a traumatic brain injury (TBI) more than two years ago.

By Whom: A nurse with experience working in the Polytrauma Clinic and OIF/OEF* Clinic at the VA in Nashville, who worked as a chaplain at the VA, and who is now completing a PhD in nursing.

Why: Partners of veterans with TBIs sometimes find themselves in new roles, encountering unanticipated challenges. If we can better understand the experience of partners we can describe it for others. Knowledge gained from this study will be used to inform people who are interested in caring for veterans and for their partners and family.

Who can Participate: Any English speaking, non-military person over 18 whose spouse or domestic partner is an OEF/OIF veteran who received a TBI over two years ago and who have been together for at least two years.

What: One interview with the researcher that will last 60 to 90 minutes. You will be given a \$25 Walmart gift card to compensate you for the time you spend participating in the study

Where: The researcher will meet you at any location of your choice such as your home, church, or public library

When: Beginning January of 2012

How: To discuss the study in more detail call or email the principal investigator, Laurel Cassidy, RN, MSN at (615) ***-**** and leave a confidential message with your name and telephone number or by email at lcassid1@utk.edu. The investigator will respond to your message as quickly as possible. Requesting further details and contacting the investigator does not require your participation in the study in any way.

Appendix E

Newspaper Ad

Are you the spouse or partner of an OEF/OIF veteran who sustained a traumatic brain injury while deployed? Are you interested in telling someone what the experience has been like for you? A nursing research study is being conducted on the experiences of spouses and partners who haven't been in the military themselves, are over the age of 18, and who have spent at least two years living with a veteran who received the diagnosis of traumatic brain injury more than two years ago. It would involve a 60 to 90 minute, one time interview, at any location of your choice, where you would be asked to share the story of your experience. You will be given a \$25 Walmart gift card to compensate you for the time you spend participating in the study. Please contact the principal researcher, Laurel Cassidy, RN, MSN, by email lcassid1@utk.edu, telephone or text, ***-***-**** for additional details. Contacting the researcher does not require you to participate in any way.

Appendix F

Resources for further information and support

- VA Caregiver Support Services <http://www.caregiver.va.gov/>
Caregiver Support Line 1-855-260-3274
- Caregiver Support Services
Tennessee Valley Healthcare System-Nashville Campus
1310 24th Ave South
Nashville, TN 37215
Contact Kathryn Elbrink, 615-873-8193 or Tammy Catalano 615-225-4989 for further information on program services
- Vet Center Nashville area; provides counseling for veterans and their significant others
1420 Donelson Pike, Suite A-5
615-366-1220
<http://www2.va.gov/directory/guide/facility.asp?id=5446>
- Lazarus Project
510 College St
Clarksville, TN 37040
No insurance necessary, no cost counseling for vets, active duty personnel and their families
Contact Rev.Jodi McCullah at 931-***-****
- *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*
<http://www.traumaticbraininjuryatoz.org/getdoc/d79e7156-01be-407c-802b-aa530b1adff3/Caregivers-Guides.aspx>
- Defense Centers of Excellence for Psychological health and Traumatic Brain Injury (DCoE) <http://www.dcoe.health.mil/ForFamilies.aspx>
- The Defense and Veterans Brain Injury Center (DVBIC) www.dvbic.org
The mission of the Defense and Veterans Brain Injury Center (DVBIC) is to serve active duty military, their dependents and veterans with traumatic brain injury (TBI) through state-of-the-art medical care, innovative clinical research initiatives and educational programs.
- Department of Veterans Affairs (VA) Web Sites: www.va.gov
OEF/OIF/OND Clinics for veterans at Nashville VA 615-327-4751
Additional VA clinics in Bowling Green, Hopkinsville, Clarksville, and Cookeville. Go to <http://www.tennesseevalley.va.gov/> for listing of clinic locations and phone numbers.
The clinics will have up-to-date information regarding additional services for families.

- America's Heroes at Work <http://www.americaheroesatwork.gov/>
This organization focuses on employment challenges of returning service members living with Traumatic Brain Injury (TBI) and/or Post-Traumatic Stress Disorder (PTSD).
- Brainline.org www.brainline.org
Website developed by WETA and the Defense and Veterans Brain Injury Center. The website provides patients, families and providers with information related to preventing, treating, and living with TBI.
- Brain Injury Association of America www.biausa.org
Founded in 1980, the mission of the BIAA is "Creating a better future through brain injury prevention, research, education and advocacy." This site includes extensive resources and many links to related websites.
- Wounded Warrior Project <http://www.woundedwarriorproject.org>
The WWP seeks to assist those men and women of our armed forces who have been severely injured during the conflicts in Iraq, Afghanistan, and locations around the world.
- The National Resource Directory <https://www.nationalresourcedirectory.org/>
The National Resource Directory is a web site for wounded, ill and injured service members, veterans, their families and families of the fallen, and those who support them. The Directory provides over ten thousand services and resources available through governmental and non-governmental organizations to support recovery, rehabilitation and reintegration into the community.

Additional web sites which may have helpful information

- Fallen Heroes Fund
<http://fallenheroesfund.org>
- Family Caregiver Alliance/ National Center on Caregiving
<http://www.caregive.org>
- Operation First Response
<http://www.operationfirstresponse.org/>
- Operation Comfort
<http://www.operationcomfort.org/>
- Fisher House
<http://www.fisherhouse.org/programs/heroMiles.shtml>

Appendix G

Interdisciplinary Phenomenology Research Group Pledge of Confidentiality

As a member of the Interdisciplinary Research Phenomenology group, I understand that I will be reading transcriptions of confidential interviews of the study “Partners of Veterans with a Traumatic Brain Injury: The Lived Experience”. The information in these transcripts has been revealed by research participants who participated in this research study with the understanding that their interviews would remain confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these transcriptions with anyone except the primary investigator, Laurel Cassidy, MSN, RN, of this project, her doctoral chair, or other members in this group. Any violation of this agreement would constitute a serious breach of ethical standards and I pledge not to do so.

Interdisciplinary Phenomenology
Research Group Member

Date

Appendix H

Transcriber's Pledge of Confidentiality

As a transcribing typist of this research project, "Partners of Veterans with a Traumatic Brain Injury: The Lived Experience," I understand that I will be hearing tapes of confidential interviews. The information on these tapes has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentially agreement. I hereby agree not to share any information on these tapes with anyone except the primary researcher of this project. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

Transcribing Typist

Date

Vita

Laurel Cassidy was born in Aurora, Illinois. She received her Bachelors of Science in Nursing from Rush University in Chicago, IL following which she moved to Tennessee to work with the Appalachian Student Health Coalition and at Nashville General Hospital. Returning to graduate school at the University of Alabama in Birmingham, Laurel received her M.S.N as a Clinical Nurse Specialist in Developmental Disabilities in 1979. Over the next few years she taught pediatric nursing at Vanderbilt University and worked internationally with Non-Governmental Organizations delivering medical care in developing countries. In 1984 she started teaching nursing at the University of Southern Mississippi where she taught for a few years prior to taking a respite from working outside the home to stay home with her three young children. A return to the work force in 1996 was preceded three years of graduate study at Vanderbilt Divinity School resulting in a M.Div. and ordination as a Unitarian Universalist minister. Laurel started working at the Veterans' Affairs Tennessee Valley Health Care System in Nashville, TN first as a chaplain, then a readjustment counseling therapist. She left briefly in late 2001 to work with Alive Hospice as a home care chaplain for a few years. Following that, Laurel started a Doctorate of Public Health in Health Behavior at George Washington University in Washington, D.C. Academic scheduling challenges necessitated her withdrawal from the program after three successful semesters. At that time, she returned to work at the Nashville VA first as a readjustment counseling therapist and later as a polytrauma nurse care manager. From 2002 to 2010 she was very active in the American Red Cross, deploying to national disasters to work in the Disaster Mental Health Services line of care. In January of 2008 Laurel found the Homeland Security Nursing Program at UTK, the perfect intersection of her interests in public health, disaster response, mental health care, and nursing. During her time in the program she took a one

year leave of absence to work with Médecins Sans Frontières (MSF)/Doctors without Borders, as a Mental Health Officer with a project in Lae, Papua New Guinea. Laurel is a member of Sigma Theta Tau Honor Society of Nursing, Phi Kappa Phi Honor Society UTK, the American Public Health Association, the American Nurses Association, and MSF-USA Association. She was awarded the Nashville Chapter American Red Cross, Exceptional Service and Dedication Award. Her research dissertation was entitled, *“It Transforms All of You”: Lived Experiences of Partners of Iraq Combat Veterans with Traumatic Brain Injuries*. A Doctor of Philosophy with a concentration in Global Disaster Nursing was awarded to Laurel by the University of Tennessee Knoxville during the summer of 2012. Shortly thereafter, she resumed her employment with MSF, headed to work with Rohingya refugees on the Bangladesh/Myanmar border.